



THE UNIVERSITY *of* EDINBURGH

This thesis has been submitted in fulfilment of the requirements for a postgraduate degree (e.g. PhD, MPhil, DClinPsychol) at the University of Edinburgh. Please note the following terms and conditions of use:

This work is protected by copyright and other intellectual property rights, which are retained by the thesis author, unless otherwise stated.

A copy can be downloaded for personal non-commercial research or study, without prior permission or charge.

This thesis cannot be reproduced or quoted extensively from without first obtaining permission in writing from the author.

The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the author.

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given.

**UK Paediatricians' medical decision-making for
severely disabled children**

A socio-legal analysis

Zoe Picton-Howell

Doctorate in Philosophy

I declare that this thesis has been composed solely by myself and that it has not been submitted, in whole or in part, in any previous application for a degree. Except where states otherwise by reference or acknowledgment, the work presented is entirely my own.

Dated 31st January 2018

ACKNOWLEDGMENTS

It was a real privilege to have the guidance and support of my supervisors Professor Graeme Laurie and Professor Sharon Cowan. I would like to thank them for their insights, wisdom, and for all their support and guidance.

Special thanks are also due to all the doctors and nurses who assisted with this study, whether in the pilot, in the survey, or the interviews. Thank you all for giving your time and sharing your thoughts and insights so generously.

I would also like to thank my NHS friends and colleagues who have supported me through this thesis and discussed the issues it explores both formally, on committees, and informally, as friends. There are far too many to mention everyone, but mention must be made of and special thanks given to, Kath Evans, Dr John Walsh, Dr Carmen Soto, Dr Karen Horridge, Dr Ruth Bromley, Dr Emily Harrop and especially Dr Tina South, for your continuous insightful encouragement and support.

I would also like to express my heartfelt gratitude to my husband Paul for his constant love, encouragement and support and also to my dear supportive friends Teresa Catto-Smith and Elizabeth Hollier.

Finally, I would like to thank my beloved son Adam, a much missed, highly talented young man, who achieved more in his short life than most do who live to old age. Adam inspired not just this thesis, but also thousands of health professionals throughout his life and continues to do so. Adam this thesis is part of your legacy.

**Dedicated to
Adam Alexander Bojelian
20th January 2000-24th March 2015**

Abstract

This thesis aims to illuminate how paediatricians in the United Kingdom (UK) make difficult medical decisions when treating severely disabled children with complex health conditions. In particular, it examines the part played, if any, by law, rights, and ethics in those decisions. After drawing on jurisprudence of the English and European Human Rights Court, together with existing scholarship, to analyse the doctors' decision making, this thesis adopts a legal consciousness theoretical approach. Using this it looks at how the paediatricians make sense of and conceptualise law when making these decisions. It examines how decisions are, by the paediatricians' own accounts, commonly made at present and what the paediatricians say about how they and their colleagues make such decisions.

This thesis addresses the following research questions:

- i) Which decisions do UK paediatricians find particularly difficult when working with disabled children and what makes those decisions particularly difficult?
- ii) What factors do UK paediatricians take into consideration when making difficult decisions for disabled children and what weight do they put on those factors?
- iii) What formal education in law, rights, and ethics have the doctors received and to what extent, if any, can we discern how this education impacts on their difficult decisions for disabled children?
- iv) How do UK paediatricians construct and understand the law, rights, and ethics when making their difficult decisions?

This thesis makes an original contribution, being the first in-depth socio-legal study examining UK paediatricians' medical decision-making for severely disabled children, by identifying two distinct styles paediatricians adopt when approaching best interest decisions, and by recommending a new category of legal consciousness. It concludes by recommending research and changes both in doctors' training and approach to best interest decision-making to address the current challenges paediatricians describe facing when deciding for severely disabled children.

Lay Abstract

This study is interested in how doctors who work with severely disabled children in the UK decide when they should treat a child who is very sick and when the doctors think it is kinder, (referred to in law as in a child's best interests), not to treat the child, but allow him or her to die.

The author surveyed thirty-three senior doctors from around the UK, who work with disabled children, making these types of decisions in their day-to-day work. The author asked the doctors in detail about how they decide for a child. The doctors were asked who he or she involved in the decision-making, what the doctor considered, and how the doctor decided what things were most important when making the decision.

Nine of the doctors also gave in-depth interviews to the researcher, talking about how they and their doctor colleagues make these types of decisions.

This research was particularly interested in how aware the doctors are of the law and the guidance they receive from their professional organisations, telling them how these decisions should ideally be made. The researcher was also particularly interested to know how important the doctors thought the law was to their decisions. Also, what did the doctors think about the law? Did the doctors think it helped them make the decisions or did it get in the way of making good decisions? Is the law something the doctors embraced or feared?

The research found that doctors divide into two groups when making these decisions. One group, who tend to be doctors who already know the children, tend to involve a lot of other people including other health staff who know the child, the child's parents and if the child is able to be part of the discussions, also the child. These doctors also think about the child's welfare widely, not just about medical things. The second group of doctors tend to be doctors who don't already know the child and tend to be called in because they are experts in caring for very sick children. They tend to have rules they have created for themselves to help them make their decisions about severely disabled children. For example, lots of the doctors talked about doctors having a rule that they would not give intensive care to a child who has learning difficulties.

There was a lot of discontent from the doctors in both groups about the way decisions are often made for severely disabled children, so this thesis ends with making some recommendations for further research and also changes in how doctors are trained and how they make their difficult decisions for severely disabled children. The aim of these recommendations is to address the problems the doctors had highlighted.

Cases Cited

A Local Authority and An NHS v MC & FC & C [2017] EWHC 370
A NHS trust v MB [2006] EWHC 507 (Fam)
Airedale N.H.S. Trust v Bland [1993] A.C. 789 House of Lords
An NHS Trust v MB [2006] EWHC 507 (Fam)
An NHS Trust v SR [2012] EWHC 3842 (Fam)
Central Manchester University Hospitals NHS Foundation Trust v A & Others [2015] EWHC 2828 (Fam)
County Durham and Darlington NHS Foundation Trust v SS, FS and MS [2016] EWHC 535
D v United Kingdom [1997] 24 EHRR 422
Gard v United Kingdom (Admissibility) (397993/17) [20017] 2 F.L.R 773; (2017) 157 B.M.L.R. 59; [2017] 65 E.H.R.R. SE9
Glass v UK [2003] ECHR Admissibility Decision no. 61827/00
Glass v United Kingdom [2004] (61827/00) 1 F.L.R 1019
Glass, R (on the application of) v Portsmouth Hospitals NHS Trust [1999] EWCA Civ 1914
Glass, R (on the application of) v Portsmouth Hospitals NHS Trust [1999] EWHC Admin 343
Great Ormond Street Hospital v Constance Yates, Chris Gard, Charles Gard [2017] EWHC 972 (Fam)
Great Ormond Street Hospital v Yates & Gard [2017] EWHC 972 (Fam)
Great Ormond Street Hospital v Yates [2017] EWCA Civ 410
Hugh Jordan v UK 24726/94 [2001] ECHR 327 (4 May 2001)
India & Ors v SSHO [2015] EWCA Civ 40
J v C (An Infant) [1970] AC 668, [1969] UKHL 4, [1969] 3 WLR 868, [1969] 3 All ER 1140
King's College Hospital NHS Foundation Trust v MH [2015] EWHC 1920
King's College Hospital NHS Foundation Trust v Y ND MH [2015] EWHC 1966
M N v SSHD [2005] UKHL 31
McCann & Others v UK [1995] 18984/91 (European Court of Human Rights, September 27 1995)
McShane v UK [2002] 43290/98, ECHR 469 (European Court of Human Rights, May 2002)
N v UK [2008] 47 EHRR 39
Osman v UK [1998] 23452/94 ECHR 101 (28 October 1998)
Portsmouth Hospitals NHS Trust v Wyatt [2005] EWHC 117 (Fam), (2005) All ER (D) 294 (Jan);
Portsmouth NHS Trust v Charlotte Wyatt [2005] EWHC 117 (Fam)
Portsmouth NHS Trust v Charlotte Wyatt [2005] EWHC 117 (Fam), para 25
Pretty v United Kingdom [2002] All ER (D) 286 (Apr), 29th April 2002
R (Mencap) v Parliamentary & Health Service Ombudsman [2009] EWHC 3559 Admin, [2010] EWCA R v Arthur (1981) 12 BMLR 1, heard before Farquharson J, 3-5th November, 1981

R(Burke) v The General Medical Council [2005] EWCA 1003
Re AA [2014] EWHC 4861
Re Ashya King [2014] EWHC 2964
Re B (A Minor) (Wardship, Medical Treatment) [1981] CA, August 1981, WLR 1421
Re C (A Child) (HIV Testing) [2000] 2WLR 270
Re J (A Minor) (Wardship: Medical Treatment) [1991] [1991] Fam. 33, [1991] 2 W.L.R. 140
Re OT [2009] EWHC 633 (Fam)
Re S (A Minor) (Medical Treatment) [1993] 1FLR 376
Re W (A Minor) (Medical Treatment) [1993] Fam 64, [1992] 4 All ER 627, [1992] 3 WLR 758, [1993] 1 FLR 1
T (A Minor), Re [1996] EWCA Civ
Wyatt (a child) (medical treatment: continuation of order) Re [2005] EWCA Civ 1181 [2005] 1 WLR 3995
Wyatt Re [2005] EWHC 2293 (Fam), [2005] 4 All ER 1325
Wyatt (a child) (medical treatment: parents' consent) Re [2004] EWHC 2247 (Fam), [2005] 1 FLR 21
Wyatt v Portsmouth Hospital NHS [2006] EWCA Civ 529
Wyatt v Portsmouth NHS Trust and another [2005] EWHC 693 (Fam)

Legislation Cited

Adults with Incapacity (Scotland) Act 2000
Children (Northern Ireland) Order 1995
Children (Scotland) Act 1995
Children Act 1989
Disability Discrimination Act 1995
Disability Discrimination Act 2005
Equality Act 2010
Education (Handicapped Children) Act 1970
Health and Social Care Act 2008 (Regulated Activities) Regulations 2014
Human Rights Act 1998
Medical Act 1983
The Mental Capacity Act 2005
Council of Europe, *Convention for the Protection of Human Rights and Fundamental Freedoms* (European Convention of Human Rights⁰, as amended, 1950
United Nation Convention on the Rights of Persons with Disabilities, adopted by the General Assembly of the United Nations on 13 December 2006 and was open for signature on 30 March 2007.
United Nations (1989) *Convention on the Rights of the Child*

Contents

PART ONE		1
Chapter One	Introduction	1
1.	Statement of Research	1
2.	Some preliminary definitions	2
2.1	Paediatrician	2
2.2	Children	3
2.3	Disabled	4
2.4	Difficult decisions	6
2.5	Ethics	6
2.6	Law	6
3.	Research Questions	7
4.	Thesis Structure	7
5.	How this thesis came about	10
5.1	Doctrinal developments	10
5.2	Personal Influences	12
5.3	Professional Influences	20
Chapter Two	A survey of key milestones in the development of this thesis	23
1.	Introduction	23
2.	Starting points: Kennedy -What is a medical decision?	25
3.	Breakthrough cases: Re B and the trial of Dr Arthur	34
4.	An era of children's rights? The Children Act 1989; The United Nations Convention on the Rights of the Child and the Disability Discrimination Act	43
5.	Impact of early rights legislation on the courts	50
6.	Professional guidance Introduced	52

7.	Rights become ‘mainstream’: Human Rights Act 1998	61
7.1	Article 2 ECHR	65
7.2	Article 8 ECHR	71
7.3	Article 14 ECHR	74
8.	Investigations and reports acknowledge poor care	75
9.	More rights? United Nations Convention on the Rights of Persons with Disabilities	79
10.	Impact of medical professionals’ attitudes on treatment of disabled people	82
11.	Conclusions: Key issues from the literature and this thesis’ contribution	91
11.1	Key issues	91
11.2	This thesis’ contribution	92
Chapter Three	Methodology	95
1.	Introduction	95
	Part A: Preparing for Data Generation	96
2.	Ethical issues	96
2.1	Ethical clearance	97
2.2	Participants’ status	98
2.3	Researcher’s personal status	102
2.4	Protecting the identities of the participants	104
3.	Creating the survey	105
4.	Piloting and modifying the survey	108
5.	Planning the interviews	109
	PART B– Generating the data	112
6.	The population	112
7.	Paediatric sub-specialties	115
8.	Demographics and diversity in the sample	116

9.	Geographical spread	118
10.	Identifying potential participants – Survey	119
11.	Survey response rate	121
	PART C – Analysing the data	124
12.	Analysing the survey data	124
13.	Interview recruitment	126
14.	Conducting the semi-structured interviews	128
15.	Analysing the interview data	132
16.	Study limitations	133
	PART TWO	137
Chapter Four	Who are the doctors in this study; what decisions do they find difficult; what makes those decisions difficult, and what factors do they consider when making difficult decisions for disabled children?	137
1.	Introduction	137
2.	Defining a clinical factor	139
3.	What does medical professional guidance say about decision-making for children?	142
4.	Doctors' attributes	145
	4.1 Place of work	151
	4.2 Place of undergraduate medical training	153
	4.3 Overseas training and employment	154
	4.4 Sub-specialties	154
	4.5 Duration of practice	157
	4.6 Age	158
	4.7 Ethnic origin	159
	4.8 Gender	161
	4.9 Parental status & personal experience of disability	163

4.10	Religion and faith	165
5.	Defining Difficult Decisions	167
5.1	The responses	168
5.2	Decisions to limit treatment	168
5.3	Why is withdrawing or withholding treatment mentioned so frequently?	170
5.4	What makes these decisions difficult?	171
6.	Which factors do doctors consider when making decisions?	173
6.1	Clinical factors	174
6.2	Non-clinical factors	176
6.3	Law and ethics	177
6.4	Best interests	178
7.	Further analysis	179
Chapter Five	Prognosis, Futility, Quality of Life and Cognitive Ability	181
1.	Introduction	181
2.	Analysing doctors' responses	182
3.	Prognosis	184
3.1	Defining prognosis	184
3.2	Weight attributed to prognosis	185
3.3	How is prognosis assessed?	186
3.4	How do the sub-specialties compare on prognosis?	186
3.5	How do male and female doctors compare on prognosis?	189
3.6	How do doctors with different personal experience of disability compare in their approaches to prognosis?	191
3.7	How do different generations of doctors compare in their approaches to prognosis?	193
3.8	How do doctors with and without a religious faith compare in their approaches to prognosis?	195

4.	Futility	198
4.1	Defining futility	198
4.2	Weight attributed to futility	200
4.3	How is futility assessed?	201
4.4	How do the sub-specialties compare on futility?	201
4.5	How do male and female doctors compare on futility?	202
4.6	How do doctors with different personal experience of disability compare in their approaches to futility?	203
4.7	How do the different generations of doctors compare in their approaches to futility?	204
4.8	How do doctors with and without religious faith compare in their approaches to futility?	205
5.	Quality of Life	207
5.1	Defining quality of life	207
5.2	Weight attributed to quality of life	208
5.3	How is quality of life assessed?	210
5.4	How do the sub-specialties compare on quality of life?	213
5.5	How do male and female doctors compare on quality of life?	215
5.6	How do doctors with different personal experience of disability compare in their approaches to quality of life?	217
5.7	How do different generations of doctors compare in their approaches to quality of life?	219
5.8	How do doctors with and without religious faith compare in their approaches to quality of life?	222
6.	Cognitive Ability	226
6.1	Defining cognitive ability	226
6.2	Weight attributed to cognitive ability	227
6.3	How is cognitive ability assessed?	228
6.4	How do the sub-specialties compare on cognitive ability?	228
6.5	How do male and female doctors compare on cognitive ability?	230
6.6	How do doctors with different personal experience of disability compare in their	230

	approaches to the use of a child's cognitive ability?	
6.7	How do different generations of doctors compare in their approaches to a child's cognitive ability?	232
6.8	How do doctors with and without religious faith compare in their approaches to a child's cognitive ability?	233
7.	Conclusions to be drawn about how doctors make difficult decisions for disabled children from what doctors in this study wrote about prognosis; fertility; quality of life and a child's cognitive ability	235
Chapter Six	Uncertainty and Disagreement	237
1.	Introduction	237
2.	The interviewees	239
3.	Defining uncertainty	241
3.1	Dominance of uncertainty	241
3.2	What is diagnostic and prognostic uncertainty?	241
3.3	What is moral uncertainty?	241
3.4	What is roster uncertainty?	243
4.	Prognostic and diagnostic uncertainty	244
4.1	What the doctors said	244
4.2	Discussion	246
5.	Moral uncertainty	251
5.1	What the doctors said	251
5.2	Discussion	253
6.	Roster uncertainty	256
6.1	What the doctors said	256
6.1	Discussion	258
7.	Nature of disagreements	261
7.1	What the doctors said	262
7.1.1	Disagreements between sub-specialities	262
7.1.2	Disagreements amongst PICU consultants	264
7.1.3	Disagreement between doctors from different generations	267
7.2	Discussion	268
7.2.1	Softliners and Hardliners	268
7.2.2	Softliner and hardliner characteristics	269
7.2.3	Ethical implications	271

7.2.4	Different values between different generations of doctors	274
7.3	Disagreements between doctors and parents	276
7.3.1	What the doctors said	276
7.3.2	Discussion	277
8.	Conclusions	282
PART THREE		285
Chapter Seven	Legal Consciousness	285
1.	Introduction	285
2.	Development of legal consciousness theory	288
3.	The creation of legal consciousness	291
4.	Choosing not to use the law & the impact of the unconscious on legal consciousness	297
5.	Law 'on the books' and law 'in action'	298
6.	Categories of legal consciousness	301
6.1	'Before the Law'	302
6.2	'With the Law'	303
6.3	'Against the Law'	305
7.	Criticisms of Ewick and Silbey's schema	306
8.	Developing Ewick & Silbey's schema	308
9.	Parallels between Halliday et al's study and this thesis	313
10.	Situating the doctors	315
11.	How legal consciousness theory helps in an understanding of paediatricians' best interest decisions and how this thesis contributes to legal consciousness scholarship	318
11.1	How legal consciousness helps in an understanding of best interest decisions	318
11.2	What this thesis adds to legal consciousness scholarship	320
Chapter Eight	What the doctors said (or did not say) about law, rights, and ethics in their surveys	323
1.	Introduction	323
2.	Prevalence of training and education in law, rights and ethics	328

3.	Mapping whether doctors who have studied law and ethics approach best interest decisions the same or differently from doctors who have not.	333
3.1	Prognosis, weight and legal/ethical education	334
3.2	Futility, weight and legal/ethical education	335
3.3	Quality of life, weight and legal/ethical education	337
3.4	Cognitive ability, weight and legal/ethical education	338
4.	Perceptions of the law	340
5.	When do doctors turn to the law?	342
6.	Conclusions	345
Chapter Nine	What the doctors said (or did not say) about law, rights, and ethics in their interviews	347
1.	Introduction	347
2.	Softliners	353
2.1	Perceptions of the law	353
2.2	Conceptualising and constructing best interests	354
2.3	Role of ethics	358
2.4	Role of lawyers	358
2.5	Law resolving disagreements	359
2.6	Not mentioning the law	360
3.	Hardliners	361
3.1	Dr 17	362
3.2	Dr 14	369
3.3	Dr 7	373
3.4	Dr 24	374
4.	Rights	378
5.	Conclusions	379
Chapter Ten	Summary Conclusions	381
1.	Introduction	381
2.	Summary of research findings	381
2.1	Research question one	381
2.2	Research question two	384
2.3	Research question three	387
2.4	Research question four	390
3.	Overall Conclusions	393
4.	Study Limitations	397
5.	Recommendations	398

5.1	Research recommendations	398
5.2	Recommendations for changes in law and practice	400
Bibliography		403
Appendices		417
Appendix 1	Schedule of figures included in this thesis	419
Appendix 2	Letter from SE Scotland Research Ethics Service	423
Appendix 3	Letter to potential survey participants	425
Appendix 4	Study Survey	427
Appendix 5	Letter to interviewees	435
Appendix 6	Interview Plan	437

PART ONE

Chapter One

Introduction

1. Statement of Research

This thesis will examine how paediatric consultants in the United Kingdom ('UK') make difficult medical decisions when treating children with severe disability and complex health problems. In particular, it will examine the part played, if any, by the law, rights, and ethics in these decisions. This thesis, as will be seen in chapter two, takes as its starting points (i) Kennedy's question 'what is a medical decision?'¹ and (ii) best interest decisions for children as they have been defined by the English High Court. These existing lenses are used to explore how, by their own accounts, UK paediatricians make difficult medical decisions for disabled children. A legal consciousness conceptual framework is then adopted to fill in the gaps left by the existing lenses, by examining how the paediatricians make sense of and conceptualise law when making these decisions.

Paediatric consultants are chosen as the focus of this study because of the dominant influence they have on the lives of disabled children. Basnett summed up the impact doctors have on the lives of disabled people generally:

'For disabled people, the training, attitudes and behaviour of health professionals towards them are all vital because of the important role health professionals play in many disabled people's lives (often with physicians dominant). These roles include

¹ Kennedy, I, (1979) *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, Published in an amended form Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

providing health or social care, acting as gatekeepers to treatment, influencing health policy and society and training future health professionals.²

The dominant influence medical professionals have on the lives of disabled children and their families was also recognised by McLaughlin in her study of the impact of caring on the parents of young disabled children.³

As will be seen, the empirical research conducted for this thesis demonstrates the extent or otherwise to which paediatricians act as gatekeepers to treatment for disabled children.

This chapter starts with some preliminary definitions of key terms used in this thesis, before going on to set out the research questions. The structure of this thesis is then outlined, followed by an account of the entry points that led the researcher to embark on this study.

2. Some Preliminary Definitions

2.1 Paediatrician

Paediatricians are medical doctors who specialise in the medical treatment and care of children.⁴ Since the focus of this thesis is the treatment of children the terms 'paediatrician' and 'doctor' will be used interchangeably.

² Basnett, I, (2001) 'Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467, p.452

³ McLaughlin, J, (2006) 'Conceptualising Intensive Caring Activities: the Changing Lives of Families with Young Disabled Children' 11(1) *Sociological Research Online*, <<http://www.socresonline.org.uk/11/1/mclaughlin.html>> accessed 4 July 2018

⁴ Royal College of Paediatrics and Child Health, 2016, *What is Paediatrics?*, accessed 20 January 2017, <https://www.rcpch.ac.uk/training-examinations-professional-development/paediatric-careers-and-recruitment/careers/what-paedi>

2.2 Children

This study examines the treatment and care of disabled *children*.

There is no single legal definition of a child across the United Kingdom. Article 1 of the United Nations Convention on the Rights of the Child, which was ratified by the United Kingdom in 1991, however, defines ‘child’ as

‘every human being below the age of eighteen years unless, under the law applicable to the child, majority is obtained earlier.’⁵

This thesis will, however, make a distinction between children under the age of two, who will be referred to as ‘infants’ and children from the age of two to the age of 18 years, who will be referred to as ‘children’. It is acknowledged that it is more usual for the term ‘infant’ to be used for children up to the age of one. However, it will be argued that there are important differences between children above and below two years of age, which make the determination of the child’s best interests potentially a different exercise. This distinction is also made because of the lack of focus on best interest decisions for disabled children (over two) by the English High Court up to the time of the empirical research for this thesis⁶ and by commentators. Young people, including those over the age of 16, are included within the definition of children in this study.⁷

⁵ United Nations Convention on the Rights of the Child 1989, Article 1

⁶ More recently the English High Court has turned its focus to children over the age of two years old in cases such as *Re AA* [2014] EWHC 4861 (not a dispute, but concerned with the withdrawal of treatment from a disabled child aged 12; *King’s College Hospital NHS Foundation Trust v MH* [2015] EWHC 1920 and *King’s College Hospital NHS Foundation Trust v Y ND MH* [2015] EWHC 1966 (7 year old with spinal muscular atrophy); *County Durham and Darlington NHS Foundation Trust v SS, FS and MS* [2016] EWHC 535 (7 year old); *A Local Authority and An NHS Trust v MC & FC & C* [2017] EWHC 370 (13 year old)

⁷ The Mental Capacity Act 2005 applies to children from the age of 16; see s.2 (5) (b) in England and Wales s.64 (4). This requires all decisions for those who lack capacity to be made in their best interests s.4. Adults with Incapacity (Scotland) Act 2000 applies to children from the age of 16 in Scotland see s.1 (6). Any intervention must benefit the individual concerned s.1 (2)

2.3 Disabled

The doctors in this study were asked about their treatment and care of 'disabled children'. For reasons explained in chapter three, the doctors in this study were told that the children of interest for this study were 'children with chronic health conditions and sometimes sensory and cognitive impairments. These children will sometimes have some level of neurological impairment, will often be described as having life-limiting conditions, although they will not necessarily be terminally ill. It is important, however, that disability is not conflated with illness. There are clearly many disabled adults and children who have no significant health problems. The focus of this study was however, disabled children with complex health problems. Their health problems may be severe and chronic, or they may be acute, or indeed both.

The children have lived beyond infancy, some into their teens. They would be described by health professionals as having 'a life limiting illness', one that is incurable, will shorten the child's natural lifespan, although the length of that life can vary from months to decades.⁸ Many of the children will have severe cerebral palsy, the most common cause of permanent disability in children.⁹

The children can experience:

'frequent illness due to their increased risk of epilepsy, gastrointestinal and nutritional problems and respiratory disorders compared with the general childhood population with those children who are most severely motor impaired at the greatest risk'.¹⁰

⁸ Fraser, LK, Miller, M, Hain, R, Norman, P, Aldridge, J, McKinney, PA & Parslow, RC, (2012) '*Rising national prevalence of life-limiting conditions in England*', *Pediatrics*, vol. 129, no. 40, pp. 923-929

⁹ Meehan E, Freed GI, Reid SM, Williams K, Sewell JR, Rawicki B & Reddihough DS, (2015) '*Tertiary paediatric admissions in children and young people with cerebral palsy*', *Child: care, health and development*, vol. 41, no. 6, pp. 928-937

¹⁰ Ibid

They may be dependant in their everyday lives on medical technology, 'with one in ten reliant on a gastroonomy feeding tube'.¹¹ Despite the complexity of their impairments and health problems, the children will live mostly at home, attend nursery or school, and have wide and varied life experiences.

They are children who twenty to twenty-five years ago, would probably have not have survived infancy.¹² As such, these children present new challenges for both medicine and law; not only in terms of how to care for the children; they raise ethically and legally challenging questions about when is it in a child's best interests to continue treatment and when treatment should be withheld or withdrawn.

This thesis shall use the term '*disabled children*' being the term used in the UK by government and public bodies. UK public bodies use the term to reflect the social model of disability¹³ and the fact that the children have been disabled by their circumstances. It can be contrasted with the phrase '*living with disabilities*' favoured by the United Nations ('UN') as putting the emphasis on the person or child first rather than on their impairment. While there is merit in both these formulations, the first is used because it is the most commonly used in the UK.

¹¹ Ibid

¹² McFarlane A, Mugford M (2012) 'Epidemiology' in Janet M. Rennie (ed), *Rennie & Robertson's Textbook of Neonatology*, Churchill, London

¹³ '*the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation from mainstream or social activities*', source: Shakespeare, T, 2016, 'The Social Model of Disability', in David LJ, (Ed), *The Disabilities Studies Reader*, chapter 13, Taylor & Francis, Abington, p. 196

2.4 Difficult Decisions

The doctors in this study were asked about their 'difficult decisions' for disabled children. As will be seen in chapter three, this term was used rather than asking doctors about their 'best interest' decisions, so as not to pre-empt the types of decisions doctors would choose and to avoid anticipating how they would frame and speak about the decision-making process. However, as will be seen, all but two doctors did choose to talk about end-of-life, best interest decisions. Once this finding has been discussed in chapter four,¹⁴ the terms 'difficult decisions', 'end-of-life decisions' and 'best interest decisions' are used interchangeably in this thesis.

2.5 Ethics

The term ethics is not, within this thesis, conceived within a traditional academic or medico-legal disciplinary understanding, but rather through the lens of the doctors' professional practice and guidance from the paediatrician's professional bodies most notably the Royal College of Paediatrics and Child Health ('RCPCH') and the General Medical Council ('GMC').

2.6 Law

The term law is defined widely to include, but not limited to, domestic legislation, international treaties, case law of the UK courts and the European Court of Human Rights ('ECtHR'), and soft law, such as the doctors' professional ethical guidance.

Having established these basic definitions, this chapter now turns to the research questions of this thesis and indicates in brief, where each research question will primarily be addressed within this thesis.

¹⁴ Chapter four, para 5.1, p.168

3. Research Questions

This thesis will address the following research questions:

- i) Which decisions do UK paediatricians find particularly difficult when working with disabled children and what makes those decisions particularly difficult?
- ii) What factors do UK paediatricians take into consideration when making difficult decisions for disabled children and what weight do they put on those factors?
- iii) What formal education in law, rights and ethics have the doctors received and to what extent, if any, can we discern how this education impacts on their difficult decisions for disabled children?
- iv) How do UK paediatricians construct and understand the law, rights, and ethics when making their difficult decisions?

The findings for research question (i) are presented in chapter four of this thesis; the findings from research question (ii) are presented in chapters four, five, and six; the findings from research question (iii) are presented in chapters eight and nine, and the findings from research question (iv) are also presented in chapters eight and nine.

4. Thesis Structure

This thesis is formed of three parts. Part one starts with this introductory chapter, which continues by setting out key influences that led to this study. A brief explanation is given as to why certain key texts and cases were formative. The rest of this chapter then sets out information about the author's personal and professional background that strongly influenced the start of this study, while also outlining steps taken to guard against that same background biasing this study.

Part one of this thesis continues with chapter two, surveying the key milestones in law and paediatricians' ethical guidance dealing with best interests and end-of-life decision-making that preceded this study. It starts with the seminal 1979 Astor Lecture given by Ian Kennedy.¹⁵ Chapter two¹⁶ also provides an overview of earlier studies that have considered doctors' attitudes towards disabled patients.

Chapter three concludes part one, by describing the methodology used for the empirical research in this study. It also addresses the research ethics issues this thesis raised in more detail.

In part two¹⁷ the findings from the empirical research in this study are presented. In chapter four¹⁸ the questions (i) who are the doctors in this study; (ii) which decisions do they find difficult; (iii) what makes those decisions difficult and (iv) what factors do they consider when making difficult decisions for disabled children, are answered. In chapter five,¹⁹ particular focus is given to what doctors said in their survey responses about the importance of prognosis, futility, a child's quality of life, and a child's cognitive ability to their difficult decisions. Part two concludes with chapter six²⁰ which turns to what the doctors said about disagreements and uncertainty in their interview.

¹⁵ Kennedy, I, (1979) *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

¹⁶ Chapter two, para 10, pp. 82-91

¹⁷ Chapters four -six, pp.137-284

¹⁸ Chapter four, pp.137-179

¹⁹ Chapter five, pp.181-236

²⁰ Chapter six, pp.237-284

Part three of this thesis deals with the doctors' reflections on the law. It starts in chapter seven²¹ with a discussion of legal consciousness, the theoretical framework used to analyse how the doctors conceptualise law in relation to their decisions. It is acknowledged that a conceptual framework is more commonly presented earlier in a thesis. However, while the questions what and how doctors make their decisions can be answered in part two of this thesis through the existing lenses of law and ethics,²² these lenses seemed unable to answer the question why doctors make decisions in the ways they do. A legal consciousness framework was therefore adopted to try to explore the question why, with an analysis of the doctors' reflections on the law in part three of this thesis.

Consideration is also given in chapter seven to how the paediatricians are situated, both in terms of how they are placed or otherwise, within legal and ethical frameworks and how they are situated within a culture of healthcare, the NHS, their hospital, department and wider culture. Chapters eight²³ and nine²⁴ then explore what the doctors wrote and said about law, rights and ethics in their survey and interviews respectively. In chapter ten,²⁵ the final chapter of part three and of this thesis, conclusions are drawn and consideration is given to the place, if any, of law in doctors' difficult decisions for disabled children. Consideration is also given as to whether changes are needed in how best interest decisions are made for disabled children in the UK, including whether changes are needed in the legal process and, if so, what these might be.

²¹ Chapter seven, pp. 285-321

²² see para 1, p.1, ante

²³ Chapter eight, pp.323-346

²⁴ Chapter nine, pp.347-380

²⁵ Chapter ten, pp. 381-403

5. How this thesis came about

This section presents the various entry points for the commencement of this thesis, to situate the researcher and explain the key influences that motivated and guided the thesis.

5.1 Doctrinal developments

This study uses mixed methods approach to research. One initial starting point was desk-based research, which was used to review relevant academic papers, statutes, international human rights conventions, professional guidance, and the case law of the English High Court and the ECtHR.

Kennedy's 1979 Astor Lecture,²⁶ in which he posed the question, 'what is a medical decision?' has already been mentioned as one of the key academic papers that guided the development of the thesis. The lecture, and the debate it inspired, are discussed in detail in chapter two.²⁷ Many of the questions Kennedy poses, such as what types of decisions are legitimate ones for doctors to make and whether doctors have the education and training to make them, are particularly pertinent to disabled children. This pertinence arises in part because of the lack of autonomy disabled children experience and, as Basnett's earlier²⁸ quotation²⁹ suggests, the dominant influence doctors can have on disabled people's lives generally and, as will be argued in chapter two, disabled children's in particular.

²⁶ Kennedy, I, (1979) *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

²⁷ chapter two, para 2, pp.25-34

²⁸ See page one ante

²⁹ Basnett, I, (2001) 'Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467

The question as to whether doctors have the training and education to make certain decisions was also raised at the admissibility hearing before the ECtHR in litigation concerning David Glass.³⁰ The case considered whether doctors were acting within their powers by treating a child in clear contravention of the child's mother's wishes without first seeking authority from the court. At its centre was 12-year-old David, a boy with significant physical and cognitive impairment. His lawyers argued:

'it is inappropriate and unreasonable to leave the task of balancing fundamental rights to the doctors. They have no training in such a task, which is pre-eminently a judicial function.'³¹

The Glass litigation³² and the academic debate that followed are discussed in detail in the next chapter.³³ They were influential in the development of the research questions in this thesis, being the only contemporary case³⁴ to cover the issues this thesis explores head on.

Conflict between the medical team and David's family, and uncertainty as to David's prognosis, featured strongly in the events that led to the *Glass* litigation.

The impact *Glass* and the debate it provoked in guiding the argument herein can be seen explicitly in research question three, which draws directly on Kennedy's argument, and the assertion made in *Glass*, that doctors do not have training to make what can be seen as legal and ethical rather than medical decisions. The paediatricians in this study

³⁰ *Glass v UK* [2003] ECHR Admissibility Decision no. 61827/00

³¹ *Ibid*

³² *Glass, R (On the application of) v Portsmouth Hospitals NHS Trust* [1999] EWCA Civ 1914; *Glass, R (On the application of) v Portsmouth Hospitals NHS Trust* [1999] EWHC Admin 343; *Glass v UK* [2003] ECHR Admissibility Decision no. 61827/00

³³ Chapter two, para 7, pp. 61-75

³⁴ see FN 6 ante

were directly asked about their training and education in law, rights, and ethics. In chapters eight and nine³⁵ what the doctors say about making best interest decisions for disabled children is also mapped against how much legal and ethical education individual doctors have received.

It is perhaps worthy of comment that David Glass and Charlotte Wyatt, a disabled infant at the centre of repeated best interest applications to court,³⁶ were both treated in the same hospital, St Mary's, Portsmouth. This does beg the question as to whether there was something about the culture of that hospital which led to disputes between families of disabled children and medical staff becoming particularly antagonistic. The impact of the culture of different medical schools, hospitals, departments, and paediatric sub-specialisms is another theme that emerges in this thesis and is explored in chapters two,³⁷ six³⁸ and seven.³⁹

5.2 Personal Influences

Although this thesis is not written in the first person, for reasons that will become obvious the following sections of this chapter are written in the first person.

My personal background as the mother to my son Adam was a profound influence on my embarking on this thesis. Adam, who lived with severe physical impairment, multiple, and very complex health problems was largely

³⁵ Chapter eight pp. 323-346, chapter nine, pp.347-380

³⁶ *Wyatt (a child) (medical treatment: parents' consent) Re* [2004] EWHC 2247 (Fam), [2005] 1 FLR 21; *Portsmouth Hospitals NHS Trust v Wyatt* [2005] EWHC 117 (Fam), [2005] All ER (D) 294 (Jan); *Wyatt v Portsmouth NHS Trust and another*, [2005] EWHC 693 (Fam); *Wyatt (a child) (medical treatment: continuation of order) Re*, [2005] EWCA Civ 1181, [2005] 1 WLR 3995; *Wyatt Re*, [2005] EWHC 2293 (Fam), [2005] 4 All ER 1325; *Wyatt v Portsmouth Hospital NHS*, [2006] EWCA Civ 529

³⁷ Chapter two, para 8, pp. 75-79 & para. 10, pp. 82-91

³⁸ Chapter six, para 4.2, p. 249

³⁹ Chapter seven, para 10, pp. 315-318

typical of the children who are the focus of this study. He was perhaps atypical in being educationally bright, with no cognitive impairment. Adam spent over eight years of his life in hospital, which in turn meant that I have spent over eight years of my life in children's hospitals, engaging with medical and nursing staff and for much of the time sitting observing. Adam was born in 2000 and acquired severe cerebral palsy shortly after his birth. He later acquired significant complex health problems. Adam died, (while I was researching this thesis), from sepsis in 2015.

Adam received care in seven different hospitals in the United Kingdom, a combination of district, tertiary and specialist children's hospitals. Moreover, because he had several serious health problems he was seen by specialists from several paediatric sub-specialties, including general paediatrics, neurology, respiratory medicine, endocrinology, metabolic medicine, gastroenterology, ear nose and throat, intensive care, and emergency medicine.

Over the years, it intrigued me that paediatric consultants could see the same child presenting with the same symptoms at the same moment very differently. I began wondering why this was and what influenced the doctors in their decisions and attitudes towards Adam. I perceived cultural differences not just within different hospitals, but also between departments within the same hospital. Different consultants often had completely disparate views of Adam and his state of health despite at times reviewing him within minutes of each other. At times the contrasts was extreme, with, for example, two consultants viewing Adam within minutes of each other, one declaring him fit for home and the other saying he needed admission to Paediatric Intensive Care ('PICU'). Doctors who regularly saw him also ranged in their assessment of his cognitive ability from being educationally gifted with no cognitive impairment at all, to having no awareness at all and being totally unable to communicate.

This should be read in the context of Adam's life more generally and, for example, his attendance at mainstream school. He was always at the top end of the ability range educationally for his age. He was in the top stream at secondary school. He blogged and wrote poetry and as a teenager was regularly commissioned to write by the NHS nationally and by charities. It seemed that paediatricians' totally contradictory assessments of Adam, whether of his medical or cognitive state, could not all be simultaneously correct. This led me to ponder what were doctors basing their judgments upon if not on Adam? **This in turn led to research question two in this thesis, an inquiry into what factors paediatricians take into consideration when deciding for disabled children.**

As Adam's mother, with a legal background and researching a PhD in best interest decisions, I was also invited over time to serve on numerous committees with health professionals. For example, I was a member of various committees of the Scottish National Clinical Network for Children with Exceptional Health Care Needs,⁴⁰ a member of Child Health UK Epilepsy Death review,⁴¹ a member of NICE's 'End of Life Care for Children and Young People' Expert Guidelines Committee⁴² and a specialist member of the NICE Quality Assurance Committee⁴³ for the same guideline. I was also co-opted on to various RCPCH committees including its Council⁴⁴ and Ethics and Law

⁴⁰ Scottish National Clinical Network for Children with Exceptional Health Care Needs, <<https://www.cen.scot.nhs.uk>>, accessed 25 January 2018

⁴¹ Child Health Reviews UK, (2013) '*Themed case reviews of mortality and morbidity in children and young people with epilepsy*', <<https://www.rcpch.ac.uk/child-health-reviews-uk/programme-findings/programme-findings-chr-uk>>, accessed 25 January 2018

⁴² NICE, '*End of life care for infants, children and young people with life-limiting conditions: planning and management*,' (2016) NG61, <<https://www.nice.org.uk/guidance/ng61>>, accessed 25 January 2018

⁴³ NICE, '*End of life care for infants, children and young people, Quality Standard*,' (2017) <<https://www.nice.org.uk/guidance/qs160>>, accessed 25 January 2018

⁴⁴ RCPCH <<https://www.rcpch.ac.uk/council/rcpch-council>>, accessed 26 January 2018

Advisory Committee.⁴⁵ I also served on steering committees dealing with human rights and equality for NHS Lothian. I am currently a co-lead author with two consultant paediatricians of new guidance on child death for NHS England and the Department of Health and on the advisory committee for the National Confidential Inquiry into Patient Outcome and Death (NCEPOD) child neuro-disability study.⁴⁶

These appointments and roles have given me the opportunity to work closely with doctors and other health professionals not involved with my son's healthcare and to engage with them in a different dynamic and environment than that of 'parent of sick child' and paediatrician. Both children's rights and best interests have been discussed frequently so I have had the opportunity to hear doctors discuss rights and best interests and gain insights into doctors' understanding of these concepts as they discussed them amongst themselves. This has given me greater insight into doctors' understanding of and attitudes towards the law and the role, or otherwise, they see it playing in their decisions.

From the very beginning of my research I was conscious that my personal experiences would have a significant impact on my research. The ethical issues this raised are discussed in greater detail in chapter three.⁴⁷ I was coming to my research with years of experience of having observed literally hundreds of doctors making difficult decisions about a disabled child with very complex health problems. I had seen many doctors provide my son with what I regarded as first class medical care, but I had also seen a small but significant minority treat my child in ways that distressed and horrified me. I was aware

⁴⁵ RCPCH, <<https://www.rcpch.ac.uk/what-we-do/ethics/ethics-and-law-resources/ethics-and-law-resource>>, accessed 26 January 2018

⁴⁶ NCEPOD <<http://www.ncepod.org.uk/cn.html>>, accessed 26 January 2018

⁴⁷ Chapter three, para 2, pp.96-105

that I was bringing to this research strong opinions on the matters being researched and with considerable experience of at times observing and at other times being involved in the type of difficult medical decisions which are the subject of my study.

I was also very conscious from the start that it was not a subject I could approach with total emotional detachment. As I discuss in chapter three, the question as to whether I should tell doctors I interviewed of my parental status, raised significant ethical issues. My status as Adam's mother prepared me I believe, for any potentially distressing comments doctors may make about disabled children and enabled me to remain detached.

Having to consider the impact of one's own personal experiences and having close links with the subject being researched, is not an unusual one for a researcher. Indeed, it seems unlikely that anyone would choose to embark on years of study of a topic they knew little or nothing about. I would suggest that most people choose to research subjects they have strong feelings about. As Bell identifies, there are definite advantages to being an 'inside' researcher as she terms it: -

'For example, he [the researcher] had an intimate knowledge of the context of the research and of the micro politics of the institution...He found that colleagues welcomed the opportunity to air problems and to have their situation analysed by someone who understood the practical day-to-day realities of their task'.⁴⁸

Bell is describing a researcher who is interviewing his colleagues, but while the doctors I interviewed were not aware I was a parent, they often expressed their pleasure at having the opportunity to discuss the relevant issues with me; indeed, several expressly thanked me for researching the issues. Bell also highlights that her researcher found it uncomfortable interviewing colleagues.

⁴⁸ Bell, J, (2010) *Doing Your Research Project*, fifth edition, Open University Press, Maidenhead, pp. 54-55

As a parent, the situation could be even more problematic if I were to interview doctors who treated my son. I would have felt restrained in some of the questions I asked them. I suspect, at least some of the doctors would not have felt comfortable giving me full and frank answers to my questions. As will be explained in chapter three,⁴⁹ I ask doctors personal and probing questions, not just about their background and family status, but also their religious faith. Doctors are asked to reflect on very intimate aspects of their professional practice, indeed, even the lawfulness of their or their colleagues' actions. It is likely that addressing such questions with doctors who treated my son would have inevitably changed the dynamic of our relationship and could have been very difficult for both parties. As I explain in more depth in chapter three,⁵⁰ I therefore did not include any doctor who treated my son in my research. I also did not include any doctors at all from Edinburgh's Royal Hospital for Sick Children because Adam spent a large part of his life there.

As I also explain in chapter three,⁵¹ I did discuss my survey and interview questions with doctors I knew, but only with ones who had very brief involvement in Adam's care. Just as Bell reports, the doctors with whom I discussed my research questions welcomed the opportunity to discuss the issues raised. They welcomed my research. I was fascinated by this, particularly as two of the doctors were very senior practitioners in positions of some influence locally and nationally. I was interested to find that once I embarked on my interviews, nearly every doctor interviewed expressed a similar view; namely, their thanks to me for researching the topic and on some occasions expressed almost relief at having the opportunity to discuss the issues; welcoming the fact these issues were being researched and addressed.

⁴⁹ Chapter three, para 3, pp.105-108

⁵⁰ Chapter three, para 2.3, p.103-104

⁵¹ Chapter three, para 4, p.108-109

I was struck by a sense from several of the consultants, despite their senior positions, that they felt helpless to address what they saw were failings in the healthcare of disabled children. This sense of helplessness is explored in more depth in chapter six.⁵²

There has also been an additional impact on my research due to my status as Adam's mum. I have worked on my PhD part-time. Additionally, Adam's health problems meant that the time I had to work on my PhD has been very restricted. While Adam was alive I was only able to work on it while Adam was in school, which due to his health problems, was limited. Moreover, there have been long spells when I had to abandon my research when Adam was critically ill or because his school nursing support had not been forthcoming. I was unable to work on my PhD for several months following Adam's unexpected death and the circumstances of Adam's death meant analysing and writing about the data from the doctors' surveys and interviews was very traumatic. This meant writing data chapters took considerably longer than they would have done in more normal circumstances.

On the flip side of this, when Adam was critically ill, I observed first hand doctors grappling with best interest decisions in real life and death situations. I have since reflected on these observations. The time I have spent with my son when he was critically ill has been important in helping to crystallise the key themes of my PhD: how do doctors make difficult decisions when treating disabled children with complex health problems and what part can the law, rights, ethics and professional guidance play, if any, in improving how those decisions are made and fundamentally the care such children receive?

I fully recognise that my closeness to the subject matter of my PhD legitimately calls into question my objectivity as a researcher. Academia has no doubt

⁵² Chapter six, para 5, pp. 251-256

moved on from the view expressed by Myrdal in 1969 that ‘the ethos of social science is the search for objective truth’.⁵³ Indeed, as Philips⁵⁴ and Rossman & Rallis⁵⁵ point out: what is meant by objectivity is itself subjective and will depend on the perception of the researcher or the observer. I suggest that it is more important and I am more likely to succeed, if rather than searching for research objectivity, which, in any event I and others argue is not possible, I am self-aware and reflexive about my subjective opinions, values and the influences which have brought me to my research; that I acknowledge these - which is what this chapter is aiming to do - and take steps to avoid my subjective views harming my research. The steps I have taken to do this are discussed in greater detail in chapter three,⁵⁶ but include detailed discussion of my survey and interview questions with my supervisors; discussing the same with paediatricians; and with the interviewee’s consent, making sound recordings of interviews and transcribing them in full to help ensure the doctors’ words are accurately recorded. I have attempted a mindful approach to the research, where biased selection of subjects and the data they provide is very consciously recognised as a real risk and actively avoided as far as this is ever possible.

For this thesis, it is all the more important that my personal and professional background is acknowledged, because a key question for my study is the influence the doctors’ personal, professional and academic background have on their difficult medical decisions for disabled children. It seems to me that if I am examining, in essence, the extent to which doctors are subjective in their

⁵³ Myrdal, G, (1969) *Objectivity in social research*, Pantheon, New York, p.40

⁵⁴ Phillips, DC, (1990) ‘Subjectivity and Objectivity: An Objective Inquiry’, in Eisner, EW, & Peshkin, A, (Eds), *Education: Qualitative Inquiry In The Continuing Debate*, Teachers College Press, New York

⁵⁵ Rossman, GB, (2011) *Learning in the Field: An Introduction to Qualitative Research*, Third Edition, Sage Publications, Thousand Oaks

⁵⁶ Chapter three, para 2.3, pp.103-104

professional decisions, I must be upfront about my own subjectivity or risk extreme hypocrisy.

5.3 Professional Influences

I also bring my professional training and experience as an English qualified solicitor to my research. Not only have I spent years observing the care a severely disabled child received through the eyes of a mother, but also through the eyes of a solicitor and one with particular interest in child and human rights. My observations of doctors have been coloured by my training and experience as a solicitor, a profession where respect for the law, ethics and professional conduct is paramount.

My identity as a solicitor has also impacted on the perception doctors treating my son had of me, sometimes to Adam's advantage and sometimes to his disadvantage. Some consultants expressly stated that they identify with me because of my professional status and hence felt a close bond with Adam. For other doctors my professional status has clearly been a cause for concern. There were occasions when my professional status was the first thing a doctor mentioned when called to see Adam. Indeed, I was often told by nurses and doctors I knew well, that my professional status was the first thing shared by certain staff when discussing Adam.

My status as a solicitor also meant that my son grew up in a particular social and economic environment. This enabled him, up to a point, to maximise his potential, both in terms of his health and education. This of course, is an influence that my professional status had on my son's care, rather than on my research. However, I suggest that the two are interlinked. My status as a solicitor gave me a very particular experience of parenting a disabled child with complex health problems, in many ways different, in some respects more positive and in some respects more negative, than other parents in a similar position. It is my very particular experience that led me to this thesis.

I would also suggest that my status as a solicitor has helped me to be cognisant of being overly subjective and to maintain a more professional detachment when interviewing doctors. My professional training and practice has taught and educated me to weigh up the evidence; to come to a judgment on the merits of an issue, not by ignoring the emotional impact of the decision, but by detaching myself from the emotional impact on me and others.

My awareness of the impact of my own personal and professional background on how I conceptualised best interest decisions, was influential in me asking, with research question two, what factors paediatricians consider when they make best interest decisions for disabled children.

Having established what led me to the start of this thesis, the next chapter surveys the key milestones in law and ethics that preceded it and the part they played on the development of the research questions in this thesis. It also addresses briefly the first of two overarching contributions this thesis makes to current literature, namely a better understanding of how paediatricians make difficult decisions for disabled children and the part, if any played by the law in those decisions. The second contribution this thesis makes is to suggest a new category of legal consciousness. This is addressed in chapter seven and nine.⁵⁷ Both contributions will be further unpacked throughout this thesis.

⁵⁷ Chapter seven, para 11.2, p.320, chapter nine, para 3.1, pp. 361-365

Chapter Two

A survey of key milestones in the development of this thesis

1. Introduction

This chapter surveys key academic and legal milestones in the development of law and ethics relevant to paediatricians' difficult decision-making for disabled children, from Kennedy's 1979 seminal Astor Lecture 'What is a medical decision?'⁵⁸ to April 2010 when the first surveys in this study were sent to doctors.

The aim of this chapter is not just to critically evaluate key milestones but also to illustrate the contextual timeline that led to the research questions in this thesis. This chapter presents the lens through which what the doctors in this study say about their decision-making is evaluated and highlights the questions the literature leaves unanswered that this thesis aims to address. It will be recalled from chapter one, that this thesis addresses the following research questions:

- i) Which decisions do UK paediatricians find particularly difficult when working with disabled children and what makes those decisions particularly difficult?
- ii) What factors do UK paediatricians take into consideration when making difficult decisions for disabled children and what weight do they put on those factors?

⁵⁸ Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form in Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

- iii) What formal education in law, rights and ethics have the doctors received and does this education impact on their difficult decisions for disabled children?
- iv) How do UK paediatricians construct and understand the law, rights and ethics when making their difficult decisions?

The review of the case law in this chapter is not intended to be a comprehensive account of all relevant cases, but rather to highlight key cases that illustrate how courts construct the concept of best interest decision-making for severely disabled children. This will provide a benchmark to compare how the doctors in this study say best interest decisions are actually made in hospitals around the UK.

This chapter starts by considering Kennedy's Astor Lecture, it then goes on to evaluate the breakthrough cases of *Re B (A Minor)* (1981)⁵⁹ and *R v Arthur* (1981).⁶⁰ The focus then turns to national and international child, disability and human rights legislation and the introduction of professional ethical guidance on end-of-care decision-making for children. The chapter then considers investigations into the healthcare of disabled people before reviewing research that considers the impact of doctors' attitudes on the treatment disabled people receive. It ends by summarising the findings of this review and the contribution this thesis makes. This exercise is important for the rest of the thesis because it sets the scene, showing what is already known about the impact of law, rights and ethics on difficult decisions for disabled children and what contribution this thesis makes to this debate.

⁵⁹ *Re B (A Minor) (Wardship, Medical Treatment)* [1981] WLR 1421, CA, August 1981,

⁶⁰ *R v Arthur* [1981] 12 BMLR 1, heard before Farquharson J, 3-5th November, 1981

2. Starting Points: Kennedy ‘What is a Medical Decision?’

Kennedy’s paper delivered as the Astor Lecture at Middlesex Hospital Medical School on 3rd July 1979 ‘What is a Medical Decision?’⁶¹ is chosen as the starting point for this timeline because the late 1970s and early 1980s are seen by commentators, among them Clements and Read,⁶² as when the paradigm in attitudes towards both doctors and disabled children and perhaps most importantly, doctors’ attitudes to disabled children, began to shift from one of unquestioning deference to doctors and an attitude towards disabled children where:

‘it was common practice to bring about deaths of some children with learning disabilities or physical impairments, particularly if their parents’ social or personal situation was ‘unfavourable’.⁶³

The late 1970s and early 1980s saw the coming together of several factors,⁶⁴ early challenges to unquestioning deference to doctors by Kennedy and others,⁶⁵ advances in medical technologies resulting in the survival of babies with severe impairments who would have previously died,⁶⁶ a criminal prosecution of a senior paediatrician;⁶⁷ the start of lobbying by pressure

⁶¹ Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

⁶² Clements L & Read J, (2008), ‘Demonstrably Awful- The right to life and the selective non-treatment of disabled babies and young children’, chapter 8 in Clements L & Read J, (Eds), *Disabled People and the Right to Life*, Routledge, Abington, pp.148-175

⁶³ Ibid, p.149

⁶⁴ Ibid, p.158

⁶⁵ Ibid, see also Illich, I, (1977) *Limits to Medicine*, Penguin, London

⁶⁶ Mcfarlane, A, Mugford, M, (2012) ‘Epidemiology’ in J Rennie (ed), *Rennie & Robertson’s Textbook of Neonatology*, Churchill, London

⁶⁷ *R v Arthur* [1981] 12 BMLR 1, heard before Farquharson J, 3-5th November, 1981

groups;⁶⁸ changes in policy leading to disabled people moving from institutions into the community⁶⁹ and access to education for children with cognitive impairments.⁷⁰ All of these played a role in the evolution of attitudes towards both doctors and disabled people.

Clements and Read summarise the lot of disabled children (and indeed adults) before the start of this shift in very grim terms:

‘Taken together, the overwhelmingly negative and burdensome images of living with disability, the barriers which prevented disabled people living ordinary lives, the segregated and frequently dehumanising service provision, the tendency to characterise disabled children and adults as falling outside majority definitions of personhood, and the exclusion of disabled people and disability issues from political and policy agendas may be seen as significant factors in a context where practices to curtail disabled children’s lives were legitimated.’⁷¹

McIntosh, now a retired neonatologist, describes his own and his colleagues’ attitudes in the 1970s as ‘arrogant’.⁷² He describes turning off infants’ ventilators overnight and then telling their mothers in the morning so mothers ‘would not have a disturbed night’s sleep’.⁷³

⁶⁸ Campbell, J, Oliver, M, (2013) *Disability Politics*, Routledge, Abington

⁶⁹ Department of Health and Social Security, (1971) *Better services for the mentally handicapped*, Cm 4683

⁷⁰ Education (Handicapped Children) Act 1970

⁷¹ Clements L & Read J, (2008) ‘Demonstrably Awful- The right to life and the selective non-treatment of disabled babies and young children’, chapter 8 in Clements L & Read J, (Eds), *Disabled People and the Right to Life*, Routledge, Abington, p. 160

⁷² McIntosh, N, (2017) ‘Ethics’, chapter 14 in Craft A & Dodd K (Eds), *From An Association to A Royal College: The History of the British Paediatric Association and Royal College of Paediatrics and Child Health 1988-20016*, Springer, New York, p.110

⁷³ Ibid

This thesis explores paediatricians' best interest decisions and is strongly influenced, as was discussed in the last chapter, by Kennedy's argument that some decisions made by doctors are not medical or wholly medical 'which may not properly be within the unique or special competence of a doctor qua doctor to make'.⁷⁴ It develops Kennedy's argument, in the context of decisions for severely disabled children. However, while Kennedy hypothesizes that doctors are not competent to make decisions which are essentially legal or ethical in nature, **research questions two, three and four of this thesis test Kennedy's hypothesis by asking paediatricians directly about their training and education in law and ethics and the impact of law on their difficult decisions. This thesis also maps individual doctor's education and training in law and ethics⁷⁵ with a view to ascertaining whether doctors who have had significant education and training in law and ethics construct and conceive their decisions for disabled children the same or differently from doctors who have not.**

It is noteworthy that Kennedy starts his paper by explaining why his own status as a lawyer is significant: 'I may say things which are rarely heard in the hurly-burly of medical life.'⁷⁶ Kennedy is making the point that he is bringing a non-medical perspective to an audience of medics. In doing so he is acknowledging that his perspective is coloured by his own professional training and background, but he is also planting the idea early in his talk that professionals - including by implication health professionals - are influenced in their opinions by their backgrounds; they are not making objective scientific decisions. This concept was one that is also important in this thesis. **Doctors were asked about their professional and personal backgrounds and their responses**

⁷⁴ Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, p.20.

⁷⁵ See chapter eight, pp.323-346 and nine, pp. 347-380

⁷⁶ Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, p.19.

were mapped to what the doctors said about the factors they include when making difficult decisions for disabled children and the weight individual doctors say they put on those factors. Moreover, as was seen in chapter one,⁷⁷ the author's professional and personal background are acknowledged and steps taken as far as it is ever possible⁷⁸ to avoid these from influencing this study. However, like Kennedy, this thesis employs a legal, professional and personal lens, to examine what doctors say about difficult decision-making for disabled children.

Kennedy's lecture starts by citing decisions chosen to illustrate that some decisions are clearly not within the realm of the doctor. He implies the examples given are so exaggerated that nobody would see them as legitimate decisions for doctors. However, one of Kennedy's examples is striking here, namely, 'how should children be raised?'⁷⁹ While presented for the apparent self-evident absurdity of a doctor being involved in such a decision, it should perhaps not be overlooked that doctors do have a huge amount of influence on how many disabled children are raised. At times doctors will be the prime decisions maker for disabled children, in circumstances where a doctor would not be involved at all for non-disabled children. For example, paediatricians often have significant influence over which school a disabled child attends, indeed even whether the child attends school at all; over what food the child eats; whether a child can attend social groups or activities; even in some circumstances what a child can wear.⁸⁰ As Martin et al identify:

⁷⁷ Chapter one, paras. 5.2-5.3, pp.12-21

⁷⁸ Chapter three, para. 2.3, pp. 103-104

⁷⁹ Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, p. 20

⁸⁰ For example, some shoe shops ask parents to provide a letter from a doctor confirming a non-mobile child is allowed to wear shoes; families are asked to provide doctors letters before disabled children are allowed to attend social groups such as Scouts or be an airline passenger.

‘The attitudes of health professionals also play a significant role in shaping the life-style opportunities generated for disabled people in addition to being the gatekeepers of information and services.’⁸¹

The examples of decisions given, as Kennedy identifies, are clearly not ‘medical’ decisions, but disability has arguably become so closely linked to medicine and every aspect of disabled children’s lives seen as within the domain of doctors, that doctors are seen by health, education, other authorities and even wider society, as the experts on all aspects of a disabled child’s life; including access to schools; social activities and services. Kennedy recognised, however, that decisions self-evidently not within the realm of medicine had become viewed as within doctors’ expertise, but perhaps not to the extent families of disabled children experience, even close on forty years later:

‘the conviction exists in my mind that failure to examine the question has resulted in decisions being taken by doctors which may not properly be within the unique or special competence of a doctor qua doctor to make.’⁸²

Kennedy tries to further define what constitutes a medical decision, stating: ‘I suppose the notion of ill health is most manageable if defined in purely physical terms, in terms of abnormality or impairment of function. He rightly recognises that this definition and the World Health Organisation’s definition of health⁸³ are far too broad. Indeed, a broad definition can be particularly problematic for disabled people as physical or cogitative impairment can be conflated with illness and thus seen legitimately within the realm of a doctor, as the examples given above illustrate, can commonly happen for disabled children. Alternatively, if doctors become the definers of ‘illness’, this risks everything to

⁸¹ Martin HI, Rowell MM, Reid SM, Marks MK, Reddihough, DS, (2005) Cerebral palsy :What do medical students know and believe?, *J. Paediatr. Child Health* 41, 43-47, p. 43

⁸² Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, p. 20

⁸³ ‘not the mere absence of disease, but the total physical, mental and social well-being’ Quoted Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, p.21

do with impairment becoming defined as 'medical'. Moreover, it also risks life threatening but treatable conditions experienced by people with severe impairments, being overlooked and the symptoms seen by health professionals as 'normal' for someone with severe impairment.⁸⁴

Decision-making for severely disabled infants is something Kennedy briefly addresses.⁸⁵ He cites Campbell and Duff's paper 'Deciding the care of severely malformed or dying infants',⁸⁶ which outlines the authors' views as to how decisions should be made. For their era, Campbell and Duff are arguably ahead of their time, advocating as they do, joint decision-making between clinicians and parents, with the clinician focusing 'primarily on the needs and rights of the individual infant' while taking wider welfare considerations into account. However, while recognising the difficulty of separating an individual child's needs from those of the child's family, there is an implication that the needs and rights of the family should outweigh those of the infant. There is also the suggestion that the life of an infant from an economically comfortable family may be saved, while the life of an infant from an economically deprived family would not be. Kennedy critiques Campbell and Duff, however, for their attack on non-medics threatening doctors' dominance in these types of decisions.

Campbell and Duff seem to place great faith in parents and doctors' abilities to limit the impact of their own values, interests and prejudices on their decisions. They say 'many safeguards against bad choices are already in

⁸⁴ Martin G, (2014) 'Caring for patients with intellectual disabilities', chapter 9 in Gill, P, Wright N, Brew I (Eds), *Working with vulnerable groups: A clinical handbook for GPs; Royal College of General Practitioners*, RCGP, London

⁸⁵ Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 25-26

⁸⁶ Campbell, AGM, Duff, RS (1979) 'Deciding the case of severely malformed or dying infants', *Journal of Medical Ethics*, 5(2), 65-67

existence'⁸⁷ but give no examples. As shall be seen in chapters four⁸⁸ and six,⁸⁹ disagreements between parents and doctors were raised by the doctors in this study, but perhaps surprisingly, the doctors talked a lot more about disagreements amongst doctors as to an individual disabled child's best interests.⁹⁰

Like Kennedy, Campbell and Duff were among the first to question not just who should make decisions for severely disabled infants, but also how these decisions should be made. However, they only addressed the question for **infants**.⁹¹ This may be because at that time disabled children with complex health problems tended not to survive infancy. However, a search of both medical and legal literature shows that little is written, even more recently about withdrawing or withholding treatment from severely disabled **children** beyond infancy. In part, this is because death in infancy is more prevalent than death during the rest of childhood.⁹² However, children with neurological conditions clearly do die between the ages of 2-18 years following the withholding or withdrawing of care. Indeed, the RCPCH 2015 guidance on end-of-life decision-making for children states that most child deaths in intensive care

⁸⁷ Ibid, p.66

⁸⁸ Chapter four, para 5.4, p.172

⁸⁹ Chapter six, para 7.3, pp. 276-282

⁹⁰ See chapter six, para 7, pp.261-275

⁹¹ Defined for the purposes of this thesis as children under the age of two years, see chapter one, para 2.2, p. 2

⁹² Figures from the Office of National Statistics and the National Records of Scotland indicated that between 1980 and 2010 102,119 children between 1-18 years died and 106,558 neonates (babies up to their first birthday) died in England, Wales and Scotland. Source, Royal College of Paediatrics and Child Health & University College London (2013) *Child Health Reviews- UK – Overview of child death in the four UK countries*, RCPCH, London

result from decisions with withdraw or withhold treatment.⁹³ Moreover, the Child Health Review UK⁹⁴ epidemiological overview into the deaths of children over the age of one, published in 2013, shows that while two thirds of the children who died in Great Britain⁹⁵ had a chronic condition, between 30%-40% of them had a predominate neurological condition. **This thesis therefore moves on from the majority of the literature, which even recently tends to address just the situation for infants.⁹⁶ Rather, this study looks at doctors,' particularly UK paediatric consultants,' decision-making for severely disabled *children* defined, in chapter one, to include young people up to the age of 18 years old.⁹⁷**

In a second paper also published in 1979,⁹⁸ Campbell and Duff considered the factors they believe doctors should include in their best interest decisions. They suggest treatment should be withheld or withdrawn if a child does not have sufficient cognitive ability 'to allow a personal life of meaning or quality and no potential for development in harmony with 'Fletcher's indicators of

⁹³ Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J, (2015) 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice', *Archives of Disease in Childhood*, 100, s1-s23, para 2

⁹⁴ RCPCH, (2013), *Child Health Reviews – UK, Clinical Outcome Review Programme, Overview of child deaths in the four UK countries*, RCPCH, London, [https://www.rcpch.ac.uk/system/files/protected/page/CHRUUK_Module%20A%20low%20res%20\(2\).pdf](https://www.rcpch.ac.uk/system/files/protected/page/CHRUUK_Module%20A%20low%20res%20(2).pdf) accessed 26 January 2018

⁹⁵ England, Scotland and Wales

⁹⁶ See for example Warwick, C, Perera, L, Murdoch, E, Nicholl, R, (2011) Guidance for withdrawal and withholding of intensive care as part of neonatal end-of-life care, *British Medical Bulletin*, vol 98(1) pp.99-113; Cuttini, M, Casotto, V, de Vonderweid, U, Garel, M, Kollee, LA, Saracci R, (2009) Neonatal end-of-life decisions and bioethical perspectives; *Early Human development*, vol. 85(10) pp. 521-525 and Rennie, JM, Leigh B (2008) The legal framework for end-of-life decisions in the UK, *Seminars in Fetal & Neonatal Medicine*, 13, 296-300

⁹⁷ Chapter one, para, 2.2, p. 3

⁹⁸ Campbell, AG, Duff, RS, (1979) Authors' response to Richard Sherlock's commentary, *J Med Ethics* 5, 141-142

humanhood'.⁹⁹ These are listed by Fletcher as: (i) minimum intelligence; (ii) self-awareness; (iii) self-control; and (iv) a sense of time, including a sense of the past and future.¹⁰⁰ Quite apart from the question, addressed later in this chapter and later in this thesis,¹⁰¹ as to how accurately doctors can assess cognitive ability, Campbell and Duff here seem to have gone far beyond what Kennedy would see as a medical decision. They seem to suggest that doctors in effect decide what it means to be human. Likewise, while the logic of their argument, that the capacity and resources of a parent should be taken into consideration, may make sense to some, moral, ethical and indeed legal questions are raised if whether a disabled child lives or dies is decided, even in part, based on a parents' economic status.

The notion that 'quality of life' decisions are within the competence of a doctor is firmly rejected by Kennedy:

'a decision as to what quality of life is worth living is not, in my view, a medical decision, and thus not for doctors alone to make. It is a decision of great moral weight which cannot and should not be left to the discretion of the particular doctor or teams of doctors. There is nothing in the training of a doctor which makes him specially or uniquely competent to make such a decision.'¹⁰²

Almost forty years on from when Kennedy, Duff and Campbell were writing, the question as to whether doctors should make quality of life judgments remains unresolved, not just between doctors and non-medics but between doctors

⁹⁹ Ibid, p.141

¹⁰⁰ Fletcher J,(1972), Indicators of Humanhood – A tentative profile of man, *The Hastings Centre Report*, 2(5) pp. 1-4

¹⁰¹ Chapter five, para six, pp. 226-234

¹⁰² Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, p.25

themselves.¹⁰³ Indeed the findings of this thesis suggest that it is something which causes some doctors considerable moral struggle.¹⁰⁴ **This thesis therefore builds on the existing normative debate as to whether doctors *should* evaluate a child's quality of life, by asking doctors, in answer to research question two, whether doctors do in practice make quality of life decisions for severely disabled children, if so how, and whether doctors think they should be making quality of life judgments.**

Very soon after Kennedy's seminal lecture the questions he asked were explored in real life situations with the breakthrough civil cases of *Re B*¹⁰⁵ and the criminal trial of a paediatrician Dr Arthur,¹⁰⁶ as will now be discussed.

3. Breakthrough Cases: *Re B* and the trial of *Dr Arthur*

Just two years after Kennedy, Campbell and Duff were writing some of these questions moved from academic debate into the law courts, when two significant legal cases, both concerning infants were considered. The cases, one civil and one criminal, arguably left more questions than they answered, but both cases subjected doctors' decision-making for disabled children to legal scrutiny for the first time and into the public domain and media spotlight. The first case, the civil one, *Re B (A Minor)* (1981)¹⁰⁷ concerned Alexandra, a baby girl born with Down's syndrome and an intestinal blockage. Alexandra's parents had refused consent for her to have an operation to remove the blockage. In their view, it was in her best interests to die rather than to live with Down's

¹⁰³ Cohn A, (2016) Measuring quality of life, *BMJ*, 354:i3816

¹⁰⁴ Chapter six, para 5, pp. 251-256

¹⁰⁵ *Re B (A Minor)* (Wardship, Medical Treatment) [1981] WLR 1421, CA, August 1981

¹⁰⁶ *R v Arthur* [1981] 12 BMLR 1, heard before Farquharson J, 3-5th November, 1981

¹⁰⁷ *Re B (A Minor)* (Wardship, Medical Treatment) [1981] WLR 1421, CA, August

syndrome. Alexandra's doctors disagreed, so referred the case to their local authority. When the parents continued to refuse consent the local authority successfully applied for Alexandra to be made a ward of court and the Director of Social Services consented to the operation. The matter came before the High Court after a surgeon refused to carry out the operation without the parents' consent. The High Court rescinded the order making Alexandra a ward. The local authority immediately appealed to the Court of Appeal.

Templeman LJ summed up the child's predicament:

'The position now is stark...if this little girl does not have this operation she will die within a matter of days. If she has the operation there is a possibility that she will suffer heart trouble as a result and that she may die within two or three months. But if she has the operation and it is successful she has Down's syndrome, she is mongoloid, but the present evidence is that her life expectancy is short, but 20 to 30 years.'¹⁰⁸

The Court of Appeal unanimously agreed that it was in Alexandra's best interests to have the operation, upholding the appeal, once again empowering the Director of Social Services to consent to the operation. The case was said to be a watershed one as, in the words of Clements and Read:

'Templeman in his extraordinary judgment simply came down in favour of life at a time when many respected physicians and large swathes of the public...were not prepared to accord parentally rejected disabled babies that right'.¹⁰⁹

As Clements and Read identify in his short judgment, Templeman LJ 'recast the legal landscape,'¹¹⁰ putting value on the life of a disabled infant, accepting the argument that Alexandra could have a 'happy life' and holding that it was for the Court and not the child's parents to decide the child's fate.¹¹¹ The case firmly

¹⁰⁸ *Re B (A Minor) (Wardship, Medical Treatment)* [1981] WLR 1421, CA, August, per Templeman LJ

¹⁰⁹ Clements, L, Read, J (2008) *Disabled People and the Right to Life*, Routledge, Abington, p. 152

¹¹⁰ *Ibid* p.151

¹¹¹ *Re B (A Minor) (Wardship, Medical Treatment)* [1981] WLR 1421, CA, August 1421, per Templeman LJ

established the principle that the court is the ultimate decider of an infant or child's best interests, not the parents nor the doctors.

The criminal trial of Dr Leonard Arthur¹¹² took place later the same year and also concerned an infant with Down's syndrome. Dr Arthur was a senior consultant paediatrician. Following baby John's birth in June 1980, his parents rejected him due to his condition. Dr Arthur noted in John's medical notes: 'Parents do not wish it to survive. Nursing care only'. He also wrote a prescription for baby John to receive a morphine-type drug to alleviate the infant's distress.¹¹³ John died three days later. The cause of death was given as 'broncho-pneumonia due to consequences of Down's syndrome.'¹¹⁴ A Pro-Life group reported the death to the police after a member of the hospital staff alerted them to the situation. Dr Arthur was charged with John's murder. By the time of the trial John's post-mortem revealed that he had additional medical conditions, so the charge was changed to attempted murder. Dr Arthur pleaded not guilty.¹¹⁵ The prosecution argued that the John's death was caused by the medication and that Dr Arthur had intended it. It was also alleged that John had been denied both food and medical treatment. The prosecution case collapsed because of concerns about the pathologist's evidence and the judge directed the jury to acquit Dr Arthur.¹¹⁶ While conceding that Dr Arthur had acted in John's best interests, the prosecution declared:

'the time has not yet come in this country when a doctor could say:
'because you are mentally-handicapped [sic] and your parents do not

¹¹² *R v Arthur* [1981] 12 BMLR 1, heard before Farquharson J, 3-5th November, 1981

¹¹³ Brahams, D, Brahams, M (1983) The Arthur case – a proposal for legislation, *Journal of Medical Ethics*, 9, 12-15

¹¹⁴ *Ibid*

¹¹⁵ *Ibid*

¹¹⁶ *R v Arthur* [1981] 12 BMLR 1, heard before Farquharson J, 3-5th November, 1981

want you to survive, I am going to take such steps as to ensure that you do not survive'.¹¹⁷

Dr Arthur did not give evidence at his trial, but several eminent paediatricians did give evidence to support him, claiming his practice was in keeping with paediatric practice at the time. Braham and Braham summarised the evidence of one of those paediatricians in their discussion of the case;

'Some children are born with such frightful handicaps [sic] that we think it is reasonable to accept the parents' decision that in the interest of their own child, prolonging or long life is not that interest'¹¹⁸

The conflict between this view and that expressed by Templeman LJ in the earlier civil case is clear. The judge's summing up to the jury was also striking for its deference to medical professionals:

'Whatever ethics a profession might evolve they could not stand on their own or survive if they were in conflict with the law...I imagine you will think long and hard before concluding that doctors of the eminence we have heard here have evolved standards that amounts to committing a crime'¹¹⁹

The trial of Dr Arthur prompted much comment in the media,¹²⁰ professional and academic journals,¹²¹ which continues even today.¹²² Gillon used the case as the basis of a series of papers in the *British Medical Journal* introducing medical

¹¹⁷ Ibid

¹¹⁸ Ibid

¹¹⁹ Quoted in Brahams, D, Brahams, M, (1983) The Arthur case – a proposal for legislation, *Journal of Medical Ethics*, 9, 12-15

¹²⁰ For example, nightly coverage on national news bulletins such as ITN: <http://www.itnsource.com/shotlist/ITN/1981/10/21/AS211081005/?v=0> accessed 20 September 2015

¹²¹ For example, Kuhse, A, (1984) Modern Myth. That letting die is not the intentional causation of death: some reflections on the trial and acquittal of Dr. Leonard Arthur, *Journal of Applied Philosophy*, 1.1, 21-38; Gee, DJ, Green, MA, (1982) The secret defence: a case for changing the law, *British Medical Journal*, (Clinical research ed), 284.6313 415

¹²² Field, D, Deeming, J, Smith, LK, (2016) Moral distress: an inevitable part of neonatal and paediatric intensive care? *archdischild* 310268

ethics,¹²³ and Brahams and Brahams used the case to propose new legislation.¹²⁴ Although Dr Arthur was acquitted it seems to be a case which has cast a long shadow over paediatricians, with two of the doctors interviewed for this study mentioning the case.¹²⁵ Dr Arthur received significant support from the medical profession and the public. In November 1981, *The Times* newspaper reported the results of a poll for BBC's *Panorama* programme.¹²⁶ The question 'Should a doctor be found guilty of murder if, with the parents' agreement he sees to it that a severely handicapped baby dies?' can be criticised for its implicit bias, but 86% of those surveyed replied 'No'; 7% 'Don't know' and 7% 'Yes'. McIntosh also reports that following Dr Arthur's suspension 'a petition with 19,000 signatures, including three MPs called for his reinstatement'.¹²⁷

While the poll and petition undoubtedly showed public support for Dr Arthur, as Clement and Read argue, this was no doubt, like the judge's summing up, in large part a reflection of both the 'largely unchallenged position and authority of doctors'¹²⁸ and the segregated lives of disabled people, which meant the general public knew little or nothing of their lives.¹²⁹

¹²³ Gillon, R (1985) An Introduction to philosophical medical ethics: the Arthur Case, *British Medical Journal* (clinical research ed), 290.6475 1117

¹²⁴ Brahams, D, Brahams, M, (1983) Symposium 1: The Arthur case – a proposal for legislation, *Journal of Medical Ethics*, 9.1 pp.12-15

¹²⁵ Chapter nine, paras 3.2-3.3, pp. 372-373

¹²⁶ Ferriman, A, (1981), Wide Support for Down's doctor, *The Times*, 10 November, *The Times Digital Archive*, accessed 26 January 2018

¹²⁷ McIntosh, N, (2017) 'Ethics', chapter 14 in Craft A & Dodd K (Eds), *From An Association to A Royal College: The History of the British Paediatric Association and Royal College of Paediatrics and Child Health 1988-20016*, Springer, New York, p.110

¹²⁸ Clements, L, Read, J (2008) *Disabled People and the Right to Life*, Routledge, Abington, p.158

¹²⁹ *Ibid*

At first sight Re B and R v Arthur appear to be two sides of a coin. In the first, doctors were acting to save the life of an infant with Down's syndrome rejected by her parents. In the second, the parents of another infant with Down's syndrome also did not believe their disabled infant's life should be saved, but Dr Arthur withheld treatment and allowed that infant to die. However, on closer consideration the two cases are not so far apart. In Re B the surgeon also originally refused to operate on Alexandra without her parents' consent, despite knowing that not doing so would inevitably lead to her death; arguably taking a stance similar to that taken by Dr Arthur. At first instance, the judge in Re B also supported this stance, reinstating the parents' parental power to consent or decline, suggesting despite the final outcomes for the two infants, the cases were not at two extremes. Moreover, it is noteworthy that in both cases the legal judgments were in keeping with the majority of doctors' clinical judgments.

Farquarson J showed considerable deference to medical professionals in general and Dr Arthur in particular, in his direction to the jury quoted above. This was perhaps a reflection of the deference shown generally to medical professionals at the time. Templeman LJ's Court of Appeal judgment in Re B while being a ground-breaking endorsement for the rights of disabled infants also as it happened, supported the clinical judgment of the majority of Alexandra's doctors. Of course, the case only came to court because the doctors referred it to social services. What is not known is what judgment the Court of Appeal would have made if, say, it had been a nurse rather than the doctors who had alerted social services and had the doctors also thought, like Alexandra's parents, that it was in her best interests to allow her die. This is not known, but Re J (1991)¹³⁰ heard by the Court of Appeal some ten years later did address the question in another case concerning a severely disabled infant.

¹³⁰ *Re J (A Minor) (Wardship: Medical Treatment)* [1991] [1991] Fam. 33; [1991] 2 W.L.R. 140

Lord Donaldson in that case made clear that the court could not order a doctor to treat a patient contrary to the doctors' clinical judgment:

'No one can dictate the treatment to be given to the child – neither the court, parents nor doctors. There are checks and balances. The doctors can recommend treatment A in preference to B. They can also refuse to adopt treatment C, on the grounds that it is medically contraindicated or for some other reason which they could not conscientiously administer. The court or the parents, for their part, can refuse to consent treatment A or B or both, but cannot insist upon treatment C. The inevitable and desirable result is that choice of treatment is, in some measure, a joint decision of the doctors and the courts or parents.'¹³¹

The Court of Appeal here is clearly reinforcing the sanctity of an individual doctor's clinical judgment, something the courts have continued to do over the decades as autonomy (at least for competent adults) has become a dominant influence in medical law.¹³² However, as was seen, even in *Re B*, doctors can and do disagree as to what is in a particular child's best interests. Indeed, although all the doctors who gave evidence in Dr Arthur's trial said they would have acted as he did, the case was later criticised by Kennedy,¹³³ among others, for only hearing evidence from doctors who testified that they would have acted as Dr Arthur did. Arguably this gave the jury the mistaken impression that most, if not all, doctors would have done the same and that Dr Arthur's conduct was in no-way controversial. Kennedy explains that this was far from the case. He cites another poll conducted by the BBC Panorama team of UK consultant paediatricians and surgeons the same year as Dr Arthur's trial.¹³⁴ That poll suggests that none of the 340 consultant paediatricians who responded would have acted as Dr Arthur did. It suggested that the doctors

¹³¹ Ibid, per Lord Donaldson

¹³² Mason, JK, Laurie, GT (2013) *Mason and McCall Smith's Law and Medical Ethics*, (9th Edition) para 1.20, p8

¹³³ Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, p. 157

¹³⁴ Ibid pp. 157-58

took a much more child-centred approach and Dr Arthur's conduct was more unusual than the defence evidence suggested. However, as Kennedy acknowledges, doctors may report acting differently in a survey, especially one conducted by an organisation outside the medical realm, from how they really act.¹³⁵ Indeed, in the survey in this study while 91% of the doctors, as will be seen in chapters nine,¹³⁶ report the child's rights as a factor they actively consider when making difficult decisions for disabled children, there is little evidence of the doctors expressly doing this in the rest of their survey responses or subsequent interviews.

The trial of *Dr Arthur* and the case of *Re B* may not then have changed how most paediatricians treat disabled children quite much as some commentators such as Kennedy¹³⁷ and Clement and Read¹³⁸ suggest, but the cases certainly opened the treatment of severely disabled children by doctors up to legal, media and public scrutiny, as well as wider professional and academic debate, for the first time. **The aim of this thesis is, therefore not just to move the debate from infants to children, but also to bring this debate up to date, by asking senior paediatric consultants in the second decade of the millennium how they and their colleagues make difficult decisions for disabled children.**

These early cases and the discussion which surrounded them, also illustrate that presented with the same child at the same time, different doctors can and do decide very differently as to a child's best interests. In the case of a severely disabled child, as these cases vividly illustrate, this can mean the difference between life or death. As the child and everything about the child is the same,

¹³⁵ Ibid p. 158

¹³⁶ Chapter nine, para 4, p.378

¹³⁷ Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, p.157

¹³⁸ Clements, L, Read, J, (2008) *Disabled People and the Right to Life*, Routledge, Abington

this tends to suggest that the doctors' decisions are based, or at least influenced, by something other than the child. At the very least it appears that doctors are considering different factors; or putting different weight on factors; or assessing factors differently; or a combination of all three. Several later studies support this in the context of infants or disabled adults.¹³⁹ Kennedy's argument that society not doctors should not be deciding what quality of life is one worth saving, is clearly very relevant here.

It is here perhaps that the doctrine, stated so clearly by Lord Donaldson in *Re J (1991)*¹⁴⁰ that the Court will not 'dictate the treatment to be given' can be criticised. It is perhaps, (subject to all the caveats well-rehearsed by Kennedy as to what is meant by the term 'clinical judgment,') acceptable to argue that a court should not interfere with a doctor's clinical judgment. It is however, more difficult to justify the non-interference where a doctor is declining treatment 'for some other reason which they could not conscientiously administer.'¹⁴¹ The court should, as a minimum, consider, for example, what is motivating the doctor. Studies have shown that doctors can, for example, be motivated by their religious faith¹⁴² or by misinformed attitudes about disabled people's lives.¹⁴³

¹³⁹ see for example in relation to infants: Cuttini, M, Nadai, M, Kaminski, M, Hansen, G, de Leeuw, Lenoir, S, Persson, J, et al (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries, *The Lancet* 355.9221: 2112-2118 and in relation to adults: Basnett, I, (2001) 'Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467. Basnett's paper is discussed later in this chapter, being influential in the development of this thesis.

¹⁴⁰ *Re J (A Minor) (Wardship: Medical Treatment)* [1991] [1991] Fam. 33; [1991] 2 W.L.R. 140; per Lord Donaldson

¹⁴¹ *Ibid*

¹⁴² Cuttini, M, Nadai, M, Kaminski, M, Hansen, G, de Leeuw, Lenoir, S, Persson, J, et al (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries, *The Lancet* 355.9221: 2112-2118

¹⁴³ See for example: Basnett, I, (2001) 'Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467; Maclean, AR, (2000) 'The Human Rights Act 1998 and the Individual's Right to Treatment', *Medical Law International*, 4 (3-4), p. 268; Gething, L,

Arguably by showing such deference to doctors, the courts are failing in their duty to protect some of society's most vulnerable citizens. This thesis does not address the courts attitudes to doctors but this is a subject recommended for further research.¹⁴⁴ The cases discussed preceded what can be termed the era of children's rights that followed in the subsequent decade. This chapter now considers the key national and international reforms introduced during that decade and their impact, if any, on normative best interest decision-making.

4. An Era of Children's Rights? The Children Act 1989; The United Nations Convention on the Rights of the Child and the Disability Discrimination Act

The late 1980s and early to mid-1990s, a decade after Kennedy's lecture, *Re B* and the trial of *Dr Arthur*, saw children and their rights come centre stage nationally and internationally. In England and Wales, the Children Act gained Royal Assent in 1989 ('the CA'); the UK ratified the United Nations Convention on the Rights of the Child ('UNCRC') in 1991;¹⁴⁵ and the Children (Scotland) Act ('the CSA') was passed in 1995. Both section 1(1) of the CA¹⁴⁶ and section 16(1) the CSA¹⁴⁷ put the paramountcy of a child's welfare, a term arguably

(1992) 'Judgements by health professionals of personal characteristics of people with a visible physical disability', *Social Science and Medicine*, 34(7), pp. 809-815, at p. 812; Paris, M.J. (1993) 'Attitudes of medical students & healthcare professionals towards people with disabilities', *Archives of Physical Medicine and Rehabilitation*, 74 (8), pp. 818-825; Michael, J, Richardson, A, et al, (2008), 'Healthcare for all: The Independent Inquiry into Access for Healthcare for People with Learning Disabilities', *Tizard Learning Disability Review*, 13 (4), pp.28-34; Ross, T (2012) 'Disabled patients dying due to institutionalised discrimination in NHS', *The Telegraph*, 3rd January 2012

¹⁴⁴ Chapter ten, para 5.1.4, p.399

¹⁴⁵ Office of the High Commissioner United Nations Human Rights, *Status of Ratification Interactive Dashboard*, <http://indicators.ohchr.org>, accessed 7th October 2017

¹⁴⁶ 'When a court determines any question with respect to: (a) the upbringing of a child, or (b) the administration of a child's property or the application of any income arising from it, the child's welfare shall be the court's paramount consideration' s.1(1) Children Act 1989

¹⁴⁷ 'Where under or virtue of this Part of this Act, a children's hearing decide, or a court determines, any matter with respect to a child the welfare of that child throughout his childhood shall be their or its paramount consideration.' s.16 (1) Children (Scotland) Act 1995

synonymous with best interests, onto a statutory footing. While the outcome in the trial of *Dr Arthur* and *Re B* at first instance, suggested the welfare of the child was not the prime or paramount consideration in those cases, the principle of paramountcy, at least when the welfare of a non-disabled child was being considered, was not new law. More than a decade before those cases, Lord MacDermott speaking in the House of Lords case of *J v C* [1969] considered similar wording to that in the CA in the 1925 Guardianship of Infants Act, said:

‘...the child’s welfare is to be treated as the top item in a list of items relevant to the matter in question...That is the first consideration because it is of first importance and the paramount consideration because it rules upon or determines the course to be followed’.¹⁴⁸

In the much later 2007 House of Lords debate on child adoption, Lord St. John of Fawsley described best interests of the child as the ‘golden thread of English law’.¹⁴⁹

Like domestic legislation, the UNCRC also emphasises the primacy of the child’s interests. Article 3 (1) states:

‘In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.’¹⁵⁰

¹⁴⁸ *J v C (An Infant)*, [1970] AC 668, [1969] UKHL 4, [1969 3 WLR 868, [1969] 3 All ER 1140 AC 668, per Lord MacDermott

¹⁴⁹ Lord St John of Fawsley (2007), House of Lords Debate on Child Adoption, *Hansard*, Column 236; 21st January 2007

¹⁵⁰ United Nations (1989) *Convention on the Rights of the Child*, Article 3 (1)

The Scottish government claim in their guidance¹⁵¹ on the CSA that the CSA and the CA, together with the Northern Irish equivalent,¹⁵² have been ‘held up by the UK Government as putting the UNCRC into UK legislation’.¹⁵³ This is perhaps an exaggeration, as there is no parallel to most of the forty-two UNCRC rights in the domestic legislation. The guidance also claims that domestic legislation goes further than the UNCRC as the CSA and CA both make the welfare of the child paramount, whereas in the UNCRC it is only ‘a primary consideration’.¹⁵⁴ While this is true, a strength of the UNCRC over the domestic equivalents is that it applies to all the rights included in the UNCRC, whereas s.1(1) CA and s.16(1) CSA only apply to deliberations in courts or child hearings. The domestic legislation would clearly have been stronger if, similar to duties in the later Human Rights Act 1998, the paramountcy duty applied to all public authorities. That having been said, the phrase ‘best interests’ is repeatedly mentioned in some 208 pieces of UK legislation.¹⁵⁵

Also, of particular relevance to this thesis, ss.17(1) and (10) the CA and s.22 CSA imposed a duty on a local authority to safeguard and promote the interests of disabled children. Perhaps because the duty is imposed on the local authority rather than public authorities generally, a review of the literature

¹⁵¹ Scottish Government; ‘Voice of the Child’ Under the Children (Scotland) Act 1995’, *Mapping Paper, Concluding thoughts - Issues and questions*, chapter seven, vol. 1,

Scottish Government, Edinburgh <http://www.gov.scot/Publications/2002/09/14905/6740> accessed 12 August 2014

¹⁵² Children (Northern Ireland) Order 1995

¹⁵³ Scottish Government; ‘Voice of the Child’ Under the Children (Scotland) Act 1995’, *Mapping Paper, Concluding thoughts - Issues and questions*, chapter seven, vol. 1,

Scottish Government, Edinburgh <http://www.gov.scot/Publications/2002/09/14905/6740> accessed 12 August 2014, para 7.1.1

¹⁵⁴ United Nations (1989) *Convention on the Rights of the Child*, Article 3 (1)

¹⁵⁵ 208 pieces of legislation from the UK are listed in the British and Irish Legal Information Institute’s database of UK legislation, available at <http://www.bailii.org> accessed 30th January 2017

relating to children's rights and healthcare in the UK, suggests that the NHS largely saw, and continues to see, the CA essentially as legislation relating to safeguarding.¹⁵⁶ However, as Clement and Read note, this appears to be interpreted as a concern to protect children from harm from those outside the NHS:

'it would have been highly unusual for a connection to be made between widespread professional concerns over infant deaths generally and those medical practices which brought about the deaths of disabled babies. They were quite simply regarded as entirely separate matters'.¹⁵⁷

Article 23 UNCRC¹⁵⁸ also gives disabled children a right to the special care and support they need to live a full, and where possible, independent life. Article 24¹⁵⁹ gives all children a right to the highest attainable standard of health and access to healthcare. Despite the Scottish government's claim that UK legislation puts the UNCRC into law in the UK¹⁶⁰ the UNCRC is not incorporated into domestic law. This means breaches of its articles cannot be pleaded as a primary course of action before a domestic court. As a result, enforcement of UNCRC rights is extremely difficult. Indeed, it can often mean that the UNCRC is not even seen to be 'law'.¹⁶¹ However, as the United Nations explain:

'The human rights treaties are legal instruments which set international standards for promoting and protecting human rights worldwide. By

¹⁵⁶ see for example: NHS Commissioning Board (2015) *Safeguarding Policy* NHS England, London;

¹⁵⁷ Clements, L, Read, J, (2008) *Disabled People and the Right to Life*, Routledge, Abington, p. 159

¹⁵⁸ United Nations (1989) *Convention on the Rights of the Child*, Article 23

¹⁵⁹ United Nations (1989) *Convention on the Rights of the Child*, Article 24

¹⁶⁰ Scottish Government; 'Voice of the Child' Under the Children (Scotland) Act 1995', *Mapping Paper, Concluding thoughts - Issues and questions*, chapter seven, vol. 1,

Scottish Government, Edinburgh <http://www.gov.scot/Publications/2002/09/14905/6740> accessed 12 August 2014,

¹⁶¹ For example, 91% doctors in this survey reported a child's rights as important to their end-of-life decisions (chapter 9, para 4, p.378), but this included 15% of doctors who said law had no relevance at all to these decisions (chapter 8, para 4, p.342)

ratifying the treaties, States subscribe to these standards and commit themselves to implementing the rights at the national level'.¹⁶²

The UNCRC is enforced largely through the UN Committee reporting process,¹⁶³ the effectiveness of which is subject to debate. Haydon and Scruton, for example, talk of the UNCRC committee as 'powerless to enforce recommendations or act on egregious breaches.'¹⁶⁴ According to the UNCRC Committee 2008 Concluding Observations on the UK these breaches include:

- (a) no comprehensive national strategy for the inclusion of children with disabilities into society;
- (b) Children with disabilities continue to face barriers in the enjoyment of their rights guaranteed by the Convention, including in the right to access to health services, leisure and play.¹⁶⁵

In 2007 UK government reported to the UCRC committee that professionals in the UK working with children receive training in the Convention.¹⁶⁶ **This thesis drew on this claim and tested it, asking paediatricians with research question three, whether they had**

¹⁶² Office for the United Nations High Commissioner for Human Rights (2005) *The United Nations Human Rights Treaty System: An Introduction to the core human rights treaties and the treaty bodies*, Fact Sheet Number 30, United Nations, Geneva

¹⁶³ Office for the United Nations High Commissioner for Human Rights (2005) *The United Nations Human Rights Treaty System: An Introduction to the core human rights treaties and the treaty bodies*, Fact Sheet Number 30, United Nations, Geneva

¹⁶⁴ Haydon, D, Scruton, P, (2009) Children's rights: rhetoric and reality: Deena Haydon and Phil Scruton explore the deficit in effective implementation of children's rights in the UK, *Criminal Justice Matters* 76.1, pp.16-18, at p. 16

¹⁶⁵ United Nations Committee on the Rights of the Child (2008) *Forty-ninth session; Consideration of reports submitted by states parties under Article 44 of the Convention; Concluding Observations: United Kingdom of Great Britain and Northern Ireland*, CRC/C/GBR/CO/4, United Nations, Geneva, para 52

¹⁶⁶ United Nations Convention on the Rights of the Child (2008) *Committee on the Rights of the Child; Consideration of reports submitted by state parties under Article 44 of the Convention; third and fourth periodic reports of States parties due in 2007 United Kingdom of Great Britain and Northern Ireland*, CRC/GBR/4, United Nations, Geneva, paras 64-68

received training in the UNCRC or child rights.¹⁶⁷

A third law introduced in this era, the Disability Discrimination Act 1995¹⁶⁸ ('the DDA') may from its title have been expected to shift the paradigm in favour of greater protection of the rights of disabled children. However, the DDA provided at best a very half-hearted regime of statutory protection for disabled people's civil rights.¹⁶⁹ Its focus, moreover, was largely, and before significant amendment in 2005¹⁷⁰ exclusively, an adult one, focusing as it did, on protection of disabled people's employment, renting or housing and related rights and even these were within prescribed limits. Later amendments did impose a public-sector duty¹⁷¹ to actively promote equality of opportunity for disabled people, including within the NHS,¹⁷² but as the much later Court of Appeal judicial review case of *R (Mencap) v Parliamentary & Health Service Ombudsman [2009]*¹⁷³ showed, the DDA was unable to protect vulnerable individuals from poor healthcare. In that case, the DDA failed to protect adults with learning difficulties from sub-standard healthcare, even when the health was so poor as to result in the individual's death.

¹⁶⁷ Chapter eight, para 2, pp. 328-332

¹⁶⁸ Disability Discrimination Act 1995 c.50

¹⁶⁹ Pearson, C, Watson, N, (2007) Tackling Disability Discrimination in the United Kingdom: the British Disability Discrimination Act, *Journal of Law and Policy*, 23: 95-120, p. 98

¹⁷⁰ Disability Discrimination Act 2005 c.13

¹⁷¹ *Ibid* s.3

¹⁷² *Ibid* s.21B

¹⁷³ *R (Mencap) v Parliamentary & Health Service Ombudsman [2009] EWHC 3559 Admin, [2010] EWCA Civ 875*

The DDA was also criticised for requiring the claimant (as opposed to the state) to bring claims for breaches.¹⁷⁴ The UNCRC Committee's General Comment No.2¹⁷⁵ recognises the challenges children generally face in enforcing their rights, citing as it does both their developmental state and significant barriers children face in accessing the judicial system.¹⁷⁶ These barriers can be seen to be all the more challenging for severely disabled children with serious health conditions. Moreover, their parents may be unaware of their child's rights, unable to enforce them or unwilling to do so, especially if their child is dependant long term on services from the public body in question.

Irrespective of the weaknesses in the DDA described, this thesis explores the impact, if any, of a child's impairment on paediatrician's difficult decisions. Research question two,¹⁷⁷ asks the paediatricians which factors paediatricians they take into consideration when making difficult decisions for disabled children and the weight they put on those factors. In chapter five,¹⁷⁸ comparisons are made between doctors with different professional and personal characteristics as to the weight they put on the four factors including child's cognitive ability.

¹⁷⁴ Pearson, C, Watson, N, (2007) Tackling Disability Discrimination in the United Kingdom: the British Disability Discrimination Act, *Journal of Law and Policy*, 23: 95-120

¹⁷⁵ UNCRC (2002) *General Comment No.2, The role of independent human rights institutions in the promotion and protection of the rights of the child*, CRC/GC/2002, United Nations, Geneva, p. 2 para. 5

¹⁷⁶ Ibid

¹⁷⁷ Chapter one, para 3, p. 7

¹⁷⁸ Chapter five, pp.181-236

5. Impact of early rights legislation on the courts

One way to assess the impact of legislation and international human rights treaties is to look at their impact, if any, on case law. The aforementioned *Re J (A Minor)* [1991]¹⁷⁹ is a leading case on an infant's best interests from the same era. However, it was heard in October 1990 at a time when the UK had signed the UNCRC, but had yet to ratify it and before it came into force within the UK.¹⁸⁰ Likewise, although the CA had received Royal assent, it had not come into force. Moreover, J was a ward of court so the Court's duty was to determine J's best interests, rather than his rights. It is perhaps then unsurprising that the judgment makes no reference to J's rights. While the CA had no influence on his Lordships' judgment, the arguments raised more than a decade earlier by Kennedy and others do appear to have reached the Court of Appeal, with Balcombe LJ judging:

‘This co-operation is reinforced by another consideration. Doctors nowadays recognise that their function is not a limited technical one of repairing or servicing a body. They are treating people in a real-life context. This at once enhances the contribution which the court -or parents can make towards reaching the best possible decision in all the circumstances.’¹⁸¹

Balcombe LJ also made clear that J's best interests should be considered from J's point of view, making clear that this is the point of view of a severely disabled child, not that of a non-disabled child.¹⁸² The difficulties inherent in doing this are obvious. The decision-makers, be they Court of Appeal judges, paediatricians or parents, will have no experience at all of what life is like for a

¹⁷⁹ *Re J (A Minor) (Wardship: Medical Treatment)* [1991] [1991] Fam. 33; [1991] 2 W.L.R. 140

¹⁸⁰ UK government, ‘United Nations Convention on the Rights of the Child (UNCRC): how legislation underpins implementation in England, UK Gov 2010)

<https://www.gov.uk/government/publications/united-nations-convention-on-the-rights-of-the-child-uncrc-how-legislation-underpins-implementation-in-england> accessed 9 July 2018

¹⁸¹ *Ibid*

¹⁸² *Ibid*

child born with a severe impairment. Added to this, very often the children in question will be too young and/or have physical and often cognitive impairment. This makes expressing their thoughts and feelings difficult or impossible. There will be the additional problem that if care is routinely withheld from infants with certain conditions health professionals will have no or little knowledge of the lives of children with those conditions, as few if any, will survive beyond infancy.

As previously mentioned, **this thesis, with research question two, addressed the weight and indeed confidence the doctors attribute to quality of life and other factors in their assessments for disabled children**¹⁸³.

A contrast can be drawn with the earlier judgment in *Re B* where Templeman LJ cited uncertainty as to Alexandra's future as reason not to withhold treatment and Balcombe LJ's judgment here where recognition of the doctors' uncertainty as to J's future was rejected as a reason to treat him. The doctors in this study cited uncertainty as a significant factor in their best interest decisions for disabled children, most commonly seeming to suggest that uncertainty is a reason to continue treatment, as is discussed in chapter six.¹⁸⁴

Later cases concerning children's best interests did touch upon the impact of both the CA and UNCRC. For example, *Re W (A Minor)* [1993]¹⁸⁵, a case concerning whether it was in the best interests of a 16-year-old girl with anorexia nervosa to have medical treatment against her consent, held that the CA did not change the Court's inherent jurisdiction to decide for the child, irrespective of whether the child was a ward of court. In *Re S (A Minor)* [1993] the Court again confirmed its inherent jurisdiction and that the test to be applied

¹⁸³ Chapter five, pp.181-236

¹⁸⁴ Chapter six, para 3-6, pp.241-261

¹⁸⁵ *Re W (a minor) (medical treatment)* [1993] Fam 64, [1992] 4 All ER 627. [1992 3WLR 758, [1993] 1 FLR 1

is that the welfare of the child remains the paramount consideration.¹⁸⁶ The weight to be put on the UNCRC was considered in *Re C (A Child)* [2000],¹⁸⁷ a case arising from the parents of a child where the mother was HIV-positive to allow their new born baby to be tested for HIV. The rights in national and international law of the child, independent of the rights of her parents were stressed. Wilson J holding ‘The Convention does not have the force of law but assists in out interpretation and development of the law’.¹⁸⁸

The conclusion to be drawn from these earlier cases is that early rights legislation seems to have led to a greater recognition of the child’s rights by the Court but also a suggestion that this in the judges’ view did not significantly change the status quo. The second half of the same decade, however, did see guidance published by the RCPCH on withdrawing and withholding care for children, perhaps an indication of a shift from the attitude described by Clements and Reid and quoted earlier in this chapter, of a disregard for the lives of disabled infants.¹⁸⁹ This chapter now goes on to critically examine this guidance and its impact.

6. Professional Guidance Introduced

The growing public interest in doctors’ decision-making, at least for infants if not for older children, was evident in 1994 when the House of Lords Select Committee on Medical Ethics heard evidence on the withdrawal of medical treatment from infants. The British Paediatric Association’s (‘BPA’) (the forerunner of the RCPCH) Ethics Committee, which had been formed in 1979, gave evidence. It told the Select Committee that up to 30% of neonatal deaths

¹⁸⁶ *Re S (a Minor) (Medical Treatment)* [1993] 1 FLR 376, at p. 380

¹⁸⁷ *Re C (A Child) (HIV Testing)* [2000] 2 WLR 270

¹⁸⁸ *Ibid* at p. 283, para C

¹⁸⁹ Clements, L, Read, J, (2008) *Disabled People and the Right to Life*, Routledge, Abington, p.149

might result from the withdrawal of life saving medical treatment.¹⁹⁰ McIntosh tells how the Select Committee's report ('House of Lords 1994'), then led to a conference in 1996 on withdrawing and withholding care. Hosted by the BPA, it was attended by, in addition to health professionals, representatives from faith communities; disabled young adults; lawyers and ethicists.¹⁹¹ McHaffie & Fowlie¹⁹² criticised this multi-disciplinary conference approach in their analysis of the 1997 professional guidance which followed. While they saw this as a 'useful way to further thinking on the subject' they saw the conference as lacking 'the rigour of empirical data collected by scientific research.'¹⁹³ This criticism is arguably misplaced as it suggests best interest decisions are purely scientific, evidence based clinical decisions, rather than wide ranging decisions that include clinical matters, but also the child's wider welfare, law, rights and ethics. Once again, Kennedy's question as to what is a medical decision is key to the debate.

The newly established RCPCH published its guidance 'Withholding and Withdrawing Life Saving Treatment, a Framework for Practice'¹⁹⁴ in 1997 ('RCPCH 1997'). The guidance was drafted by the College's Ethics Advisory Committee, membership of which is listed at the start of the document and itself merits some comment. Even by the time of second edition, ('RCPCH 2004')¹⁹⁵ the edition of most relevance to this thesis, being current at the time of the

¹⁹⁰ McIntosh, N, (2017) Ethics, chapter 14 in Craft, A, Dodd, K, (Eds), *From An Association to A Royal College: The History of the British Paediatric Association and Royal College of Paediatrics and Child Health 1988-20016*, Springer, New York, p.110

¹⁹¹ Ibid, p.111

¹⁹² McHaffie, H, Fowlie, PW, (1998) Withdrawing and withholding treatment: Comments on new guidelines, *Archives of Disease of Childhood*, vol.79, Issue 1, pp. 1-5

¹⁹³ Ibid, p.1

¹⁹⁴ RCPCH, (1997) *Withholding and Withdrawing Life Saving Treatment, a Framework for Practice 1997*, RCPCH, London

¹⁹⁵ RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London

empirical research with paediatricians, eleven of the fourteen members of the guidelines committee were doctors and one was a nurse. The remaining three were a law lecturer,¹⁹⁶ a lay member and a Church of England minister. The names of the members suggest that only one committee member was from an ethnic minority.¹⁹⁷ Nine were male and six were female. The medic-dominated membership of the committee suggests the RCPCH saw the withdrawing and withholding of treatment as a decision made by doctors. The list of former committee members suggests there had been no greater diversity in the make-up of the committee when the guidance had been originally drafted.¹⁹⁸

The apparent scarcity of diverse viewpoints on the RCPCH drafting committee contrasts with the guidance itself. RCPCH 2004 talks about the importance of including disabled people's views and an understanding of cultural diversity.¹⁹⁹ A comparison can be made with the Nuffield Council on Bioethics Working Party, which considered ethical issues in critical care decisions for neonates,²⁰⁰ two years after RCPCH 2004. That Working Party was much more diverse, with, for example, equal numbers of men and women. Medics also did not dominate the committee, being only four of the fifteen members. The committee also included lawyers and ethicists with recognised relevant expertise and a range of non-medical specialists. However, like the RCPCH committee, the Nuffield 2006 Working Party did not appear to have any obvious

¹⁹⁶ However, the lawyer seemed to have expertise in child protection, rather than best interest decisions at the end of a child's life: <http://www.plymouth.ac.uk/staff/phil-bates> accessed 20 June 2017

¹⁹⁷ It is recognised that an individual's name is only, at best, a guide to his or her ethnic origin.

¹⁹⁸ RCPCH, (1997) *Withholding and Withdrawing Life Saving Treatment, a Framework for Practice 1997*, RCPCH, London

¹⁹⁹ RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London, Para 5.3, page 38

²⁰⁰ Nuffield Council (2006) *Critical Care Decisions in fetal and neonatal medicine: ethical issues*. Nuffield Council on Bioethics, London

ethnic or cultural diversity, which may have meant that some important diverse viewpoints were not considered.²⁰¹

RCPCH 2004, starts with a statement that ‘The background to all treatments, now and in the future, must be that **they should be in the child’s best interests.**’²⁰² The high possibility of differences of opinions between health professional, patients and families is acknowledged, perhaps a move away from the paternalism of the 1970s and 1980s, with the guidance literally highlighting **‘It is unrealistic to expect complete consensus therefore the aim is to seek as much common ground as possible while acknowledging sincerely held differences of opinion.’**²⁰³

The original RCPCH 1997 received both praise and criticism from medics. McHaffie and Fowlie while reviewing it, reported on their own empirical research into the views on end-of-life decision-making of fifty-seven medics and 119 nurses working in six neonatal units in Scotland.²⁰⁴ Their main criticism of RCPCH 1997 was that the guidance, in some respects, reflected an ideal rather than reality. For example, despite references to ‘open and timely communication’ and ‘reasoning together’²⁰⁵ they report that nurses in five out of six of the units felt insufficiently involved in discussions.²⁰⁶ They also expressed concern that the guidance did not address the issue of withholding feeding from

²⁰¹ Ibid, p.ix

²⁰² RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London, Introduction, p. 12

²⁰³ Ibid

²⁰⁴ McHaffie, H, Fowlie,PW, (1998) Withdrawing and withholding treatment: Comments on new guidelines, *Archives of Disease of Childhood*, vol.79, Issue 1, pp. 1-5

²⁰⁵ RCPCH, (1997) *Withholding and Withdrawing Life Saving Treatment, a Framework for Practice 1997*, RCPCH, London

²⁰⁶ McHaffie, H, Fowlie,PW, (1998) Withdrawing and withholding treatment: Comments on new guidelines, *Archives of Disease of Childhood*, vol.79, Issue 1, pp. 1-5

a dying infant. McHaffie and Fowlie report that nurses found doing this particularly distressing commenting ‘implementing this can feel very different from giving this’²⁰⁷ [the instruction not to feed]. They also report that many of the clinicians they interviewed were unaware that the practice of withholding feeds from infants still continued and speculate that this ‘could account for the scant attention in the RCPCH framework’,²⁰⁸ highlighting a gap between the guidance and grassroots practice. **This thesis goes further than McHaffie and Fowlie’s study by asking doctors, across the UK not just in Scotland, as part of research question four, if and how they use guidance when making decisions for disabled children, rather than, as literature does just looking at decisions for infants.**

It is noteworthy that McHaffie and Fowlie comment: ‘The RCPCH does address the concerns of clinicians.’ It is perhaps no surprise that the concern of a medical royal college is to address the concerns of its members. McHaffie and Fowlie also clearly state that the purpose of their paper was to look ‘at the RCPCH document in relation to the express concerns and stresses of staff who work in neonatal intensive care units.’²⁰⁹ It was seen earlier that the 1997 edition of the RCPCH guidance arose in response to House of Lords 1994.²¹⁰ The Select Committee had considered end-of-life care broadly, embracing ‘a wide range of legal, theological, medical, nursing and political opinions’.²¹¹ Most relevant here, however, is that they expressly considered only the withdrawing and withholding of treatment from infants not older children. The committee also stated that the withdrawal or withholding of treatment should only be lawful

²⁰⁷ Ibid, para 8

²⁰⁸ Ibid

²⁰⁹ Ibid, para 3

²¹⁰ RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London, Preface

²¹¹ Lord Walton of Detchant (1994) ‘Medical Ethics Select Committee Report’, House of Lords Debate, *Hansard*, vol 554 cc1344-412, House of Lords, London

when in the infant's best interests.²¹² It is clear from the House of Lords debate that their Lordships' concern was the protection of vulnerable infants, rather than the protection or concerns of doctors. There is a strong argument that this should also be the purpose of professional guidance, rather than as McHaffie and Fowlie suggest, 'the concerns of clinicians'²¹³ which may or may not correspond with a child's best interests. **When the doctors were asked as part of research question four about their use of professional guidance, particular consideration was given to if and how the doctors used RCPCH 2004. What doctors said in this regard will be seen in chapter nine.**²¹⁴

By RCPCH 2004 specific reference was made to disabled children; the importance of society not devaluing disabled people; that impairment is not incompatible with a life of quality; and that disabled children should be provided with high quality health care.²¹⁵ Paediatricians were also guided 'to avoid over pessimistic views about life with disability' and the guidance acknowledges that a disabled person's view of their quality of their life can be different from a non-disabled person's view of life with impairment.²¹⁶ The guidance also ends with the statement that 'All who relate to those with disability should offer them the best personal and professional care'.²¹⁷ There is, however, arguably a contradiction in these positive messages with the guidance's 'No Purpose Situation'²¹⁸ listed as one of five potential reasons given as examples of when

²¹² Ibid

²¹³ McHaffie, H, Fowlie, PW, (1998) Withdrawing and withholding treatment: Comments on new guidelines, *Archives of Disease of Childhood*, vol.79, Issue 1, pp. 1-5

²¹⁴ Chapter nine, para 3.4. p.377

²¹⁵ RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London, Para 2.7.1, page 24

²¹⁶ Ibid, Para 2.7.2, p.24

²¹⁷ Ibid, Para 6 p.40

²¹⁸ '4. The No Purpose Situation. Although the patient may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it'.

paediatricians may consider withholding or withdrawing treatment.

Unfortunately, the guidance says little about the five scenarios. There are clear parallels between the 'No Purpose' situation and the 'demonstrably awful' life rejected in *Re B*²¹⁹ and *Re J*²²⁰ as a standard for assessing whether treatment should be given. It can, it seems, be seen as no more than a description of severe impairment. As such, it seems to be questionable grounds for the withdrawal of treatment, especially in light of the positive statements made elsewhere in the guidance. Indeed, the greatest problem with RCPCH 2004 is its lack of detail. It makes highly complex issues appear deceptively straightforward.

A contrast can once again be made with the Nuffield 2006 report, which although only dealing with neonates,²²¹ succeeds much better at conveying and considering the complexity of the issues involved. Many of the issues it raises can be applied to critical care decisions for disabled children generally. It emphasises differences of opinions;²²² it recognises the limits to a doctor's knowledge²²³ and uncertainties,²²⁴ and it includes a thoughtful analysis of the social and economic impact of the decisions.²²⁵ It is perhaps, however, worthy of note that House of Lords 1994 had expressed an unanimous opinion twelve years earlier that:

'...healthcare teams should not be required to make decisions relating to

Source: RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London, p.11

²¹⁹ *Re B (A Minor) (Wardship: Medical Treatment)* [1981], 1 W.L.R. 1421, 1424

²²⁰ *Re J (A Minor) (Wardship: Medical Treatment)* [1991] [1991] Fam. 33; [1991] 2 W.L.R. 140

²²¹ Infants up to the age of 28 days

²²² Nuffield Council (2006) *Critical Care Decisions in fetal and neonatal medicine: ethical issues*. Nuffield Council on Bioethics, London, para 3, Executive Summary

²²³ *Ibid*, para 4 Executive Summary

²²⁴ *Ibid*, Chapter 1, para 1.2

²²⁵ *Ibid*, chapter 2

resources in the course of day-to-day clinical care of individual patients. Their concern should be for that individual's welfare. Decisions about treatments which society can or cannot afford should be made elsewhere than in the hospital ward or the doctor's consulting room..²²⁶

This made clear that in their view resource considerations had no place at the bedside.

While mostly praising the RCPCH 2004, Gillis,²²⁷ an Australian paediatrician writing in the *British Medical Journal*, also expressed reservations. His concern was what he saw as the 'glib response'²²⁸ of the guidelines committee to situations where medics and parents did not agree as to a child's best interests, a situation he suggested was not uncommon and which is 'a particularly difficult problem'²²⁹ Gillis is correct that the guidance even by 2004 said very little about how such disputes should be resolved; just two brief sentences.²³⁰ Indeed, the guidance can be said to be very paternalistic in this regard, as the assumption seems to be that the doctors' opinion will be the correct one and the doctor's role is to convince the parents of this, rather than balance the parents' views of the child's best interests with those of the doctors. RCPCH 2004 does state: 'Parents may ethically and legally decide on behalf of their children'²³¹ and 'the parents will always be participants in the care and decision-making.'²³² It talks of the need to support parents, in this task,²³³ but the emphasis is on helping

²²⁶ Lord Walton of Detchant (1994) 'Medical Ethics Select Committee Report', House of Lords Debate, *Hansard*, vol 554 cc1344-412, House of Lords, London

²²⁷ Gillis, J, (1997) When lifesaving treatment in children is not the answer, *BMJ* 315, pp. 1246-1247

²²⁸ *Ibid*, p.1247

²²⁹ *Ibid*

²³⁰ RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London, para 2.3.2.6 & 2.3.2.13

²³¹ *Ibid* para 2.3.2.3 p.18

²³² *Ibid* para 2.2 p. 22

²³³ *Ibid*.

parents to understanding the doctors' clinical decision, which while a vital part of the decision, should not be the whole of it. There is little to suggest that there could be any merit in exploring a parent's viewpoint. Moreover, it seems doctors are tasked with deciding whether a parent is acting in a child's best interests,²³⁴ **a task it will be argued, see for example chapter five²³⁵ is more akin to that of a judge than a medical professional.** This once again returns to Kennedy's 1979 argument²³⁶ and the crucial question of the nature of medical decisions. It also mirrors what was said by the lawyers acting for David Glass at the admissibility hearing before the ECtHR, as was seen in chapter one.²³⁷ It is worthy of note that the RCPCH guidance published in March 2015 ('RCPCH 2015')²³⁸ replacing RCPCH 2004, does address disagreements with parents in more depth. It makes clear that the courts, not doctors, should decide unresolved disagreement.²³⁹

In addressing research question one and the question what makes decisions difficult, this thesis will address what doctors said not just about disagreements between doctors and a child's parents, but also, a

²³⁴ Ibid para 2.3.2.3 p.18

²³⁵ Chapter five, para 5.8, p.225

²³⁶ Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form in Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

²³⁷ Chapter one, para 5.1, p.11

²³⁸ Neither this document nor NICE guidance published in December 2016 (NICE, 2016, *End of life care for infants, children and young people with life-limiting conditions: planning and management*, NG61, <https://www.nice.org.uk/guidance/ng61> accessed 25 January 2018) are critically analysed in this chapter as they were published after the timeline of this surveyed in this chapter and completion of the empirical research for this thesis was completed.

²³⁹ Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J, (2015) 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice', *Archives of Disease in Childhood*, 100, s1-s23

subject the doctors spoke much more about, disagreements amongst doctors as to an individual child's best interests.²⁴⁰

It does seem from RCPCH 2004 and the commentaries on it discussed, that the focus of the guidance was perhaps more about making difficult decisions easier for doctors than protecting the best interests of the child. While protection of health professionals is clearly important, this does seem to overlook the paramountcy of best interest decisions required by law. Between the first and second edition of the RCPCH guidance the Human Rights Act 1998 ('the HRA')²⁴¹ had been enacted. The HRA seemed to have little impact on the guidance, but consideration is now given as to whether the HRA did seem to impact more widely on best interest decision-making for disabled children.

7. Rights become 'mainstream': Human Rights Act 1998

The passing of the HRA was accompanied by significant government and media fanfare. On the day it came into force, BBC news described it as an act 'changing the face of the UK'.²⁴² Perhaps reflecting how significant they thought the HRA to be to healthcare, the BMJ also described it as 'a momentous development in the constitutional history of the United Kingdom'.²⁴³ The HRA incorporated the European Convention of Human Rights, ('ECHR')²⁴⁴ which the UK had ratified in 1951, into domestic law. Individuals had been able to take cases directly to the ECtHR since 1966 (after the full exhaustion of all local

²⁴⁰ Chapter six, para 7, pp.261-275

²⁴¹ Human Rights Act 1998 c 42

²⁴² BBC News, (2000), *Landmark human rights law enforced*, BBC, 2nd October 2000, <http://news.bbc.co.uk/1/hi/uk/951753.stm>, accessed 7th October 2017

²⁴³ Hewson, B (2000) Why the human rights act matters to doctors, *BMJ*, 30;321(7264):780-1,p. 780. accessed 26 Apr. 2017

²⁴⁴ Council of Europe, *Convention for the Protection of Human Rights and Fundamental Freedoms* (European Convention of Human Rights), as amended, 1950

remedies), but from October 2000 the ECHR became directly enforceable in UK courts. While the s.6 HRA²⁴⁵ duty imposed on all public authorities to ensure compliance with the ECHR saw some NHS trusts²⁴⁶ drafting rights policies with the aim of imbedding a culture of rights,²⁴⁷ the impact of the HRA for all its prominence, especially on best interest decisions for disabled children is questionable. Indeed, for all the fanfare, a study funded by the Nuffield Trust found ‘little visible impact on the field of health care provision,’²⁴⁸ resulting from its passing. Likewise, a 2003 Audit Commission report on the human rights strategies of public bodies in England and Wales found ‘In health, 73 per cent of Trusts are not taking action.’²⁴⁹ The Audit Commission report suggested that rights were seen by NHS staff, especially managers, as something raised by trouble makers and making information about rights available was seen as ‘only raising the opportunity for further litigation’.²⁵⁰

This lack of impact of the HRA seemed to extend to the jurisprudence of the English High Court on best interest decisions for children. Hedley J’s reference to the ECHR in *Portsmouth NHS Trust v Charlotte Wyatt* [2005]²⁵¹ is, perhaps somewhat surprisingly, one of the most detailed examinations of the impact of the HRA and the ECHR in such cases by the UK courts. It makes clear, at least in that case, that the HRA and ECHR changed nothing:

²⁴⁵ S.6 Human Rights Act 1998 c. 42

²⁴⁶ In Scotland, NHS boards

²⁴⁷ see for example NHS Lothians (2011) *Equality and Diversity Policy*, NHS Lothian, Edinburgh <http://www.nhslotian.scot.nhs.uk/YourRights/EqualityDiversity/Pages/default.aspx>, accessed 7 November 2017

²⁴⁸ Haggett, E, (2001) *The Human Rights Act 1998 and Access to NHS Treatments and Services: A Practical Guide*, the Constitution Unit, School of Public Policy, UCL, London, p. 6

²⁴⁹ Audit Commission (2003) *Human Rights, Improving Public Service Delivery*, Audit Commission, London, para 12

²⁵⁰ *Ibid*, para 14

²⁵¹ *Portsmouth NHS Trust v Charlotte Wyatt* [2005] EWHC 117 (Fam)

‘In the course of argument, the European Convention of Human Rights was referred to but no separate submissions were developed even though key rights were undoubtedly engaged. This is because although English domestic law has undoubtedly been significantly affected by the concept of Convention rights, it is recognised in this case at least, the Convention adds nothing to domestic law’.²⁵²

This is perhaps all the more surprising if medical law is accepted, as described by Kennedy and Grubb, ‘as a subset of human rights law.’²⁵³ Indeed, attempts to use the provisions of the ECHR by David Glass and his mother in *Glass v UK* [2004],²⁵⁴ the only UK case concerning the medical care of disabled child to reach the ECtHR,²⁵⁵ had only limited success, as shall be seen in the discussion of the case to follow.²⁵⁶

While Hedley J did preface his comment in *Wyatt* by saying ‘*in this case at least*’ the dearth of references to ECHR rights in the cases following the passing of the HRA would seem to indicate that, at least in cases concerning the withholding or withdrawal of medical care of severely disabled infants and children, that either the HRA made, as Hedley J suggested, little change to English law or the courts were overlooking the children’s rights. Unlike the UNCRC, the ECHR being mainly concerned with civil and political rights, rather than social and economic rights, has no express right to health care. However, s.6 of the HRA makes it unlawful for a public authority, which includes the

²⁵² *Portsmouth NHS Trust v Charlotte Wyatt* [2005] EWHC 117 (Fam), para 25

²⁵³ Kennedy, I, Grubb, A, (2000), *Medical Law*, 3rd Edition, Butterworths, London, at p.6

²⁵⁴ *Glass v United Kingdom*[2004] (Application No 61827/00), Fourth Section, March 9 2004

²⁵⁵ An attempt in 2017 by the parents of Charlie Gard to get the ECtHR to review the decision of the UK Court to permit artificial ventilation to be withdrawn from their son, failed at the admissibility hearing: *Gard v United Kingdom (Admissibility)* (397993/17) [20017] 2 F.L.R 773; (2017) 157 B.M.L.R. 59; (2017) 65 E.H.R.R. SE9

²⁵⁶ Chapter two, para 7, pp.61-75

NHS²⁵⁷ to act in contravention of the ECHR. Three of the ECHR articles are self-evidently the most relevant to best interest decisions for severely disabled children: Article 2, the right to life;²⁵⁸ Article 8, the right to respect for family and private life²⁵⁹ and Article 14, the right not be discriminated against in the exercise of an ECHR right.²⁶⁰ There is also a theoretical argument that Article 3 ECHR, the right not to be subjected to inhuman and degrading treatment,²⁶¹ could also be pleaded in relation to the best interests of a child on the basis that continuing treatment allowed:

suffering attributable to the progression of a disease may amount to such treatment [treatment in breach of Article 3] if the state can prevent or ameliorate such suffering and does not do so'.²⁶²

However, the argument was rejected by the ECtHR in *Pretty v UK* [2002],²⁶³ a case brought by a disabled adult arguing for a right to die. Article 3 was not pleaded by David Glass lawyers in the admissibility hearing brought before the ECtHR.

The argument was successful in the UK case involving an adult, *D v United Kingdom* [1997].²⁶⁴ A convicted drugs trafficker in the final stages of AIDS faced deportation to St Kitts. The ECtHR accepted the argument that the absence of vital medical treatment would rapidly accelerate his death and that this would

²⁵⁷ When providing NHS funded treatment: House of Lords & House of Commons Joint Committee on Human Rights (2004) *The Meaning of Public Authority under the Human Rights Act*, Seventh Report of session 2003-2004, HL paper 39, HC paper 382, 23rd February 2004, p.10.

²⁵⁸ Convention for the Protection of Human Rights and Fundamental Freedoms(1950) (European Convention on Human Rights, as amended) (ECHR), Article 2

²⁵⁹ *Ibid*, Article 8

²⁶⁰ *Ibid*, Article 14

²⁶¹ *Ibid*, Article 3

²⁶² *D v United Kingdom* [1997] 24 EHRR 422 at pp. 446-449 paras 446-449

²⁶³ *Pretty v United Kingdom* [2002] All ER (D) 286 (Apr), 29th April 2002

²⁶⁴ *D v United Kingdom* [1997] 24 EHRR 423

amount to a breach of Article 3. Subsequent cases arguing that a lack of quality medical care at a proposed destination would render a deportation to be a breach of Article 3 have failed.²⁶⁵ The ECtHR has repeatedly stressed the high bar must be met to succeed in showing a breach of Article 3.²⁶⁶ The English High Court's and the ECtHR's approach to Article 2, 8 and 14 ECHR in cases concerning the medical treatment of disabled infants and children will now be explored.

7.1 Article 2 ECHR

Parker J very briefly considered Article 2 ECHR at first instance in Re OT [2009].²⁶⁷ Infant OT had been in intensive care since he was three weeks old. He was diagnosed as having a mitochondrial condition.²⁶⁸ He had neurological impairment and required a ventilator to breath. He was also unable to suck or swallow. Drawing on current law, Parker J summarised Article 2 in this context as imposing:

‘a positive obligation to give life sustaining treatment, where responsible medical opinion is of the view that such treatment is in the best interests of the patient, it does not impose an absolute obligation to treat if such would be futile’²⁶⁹

Parker J cited with approval Re (Burke) v The General Medical Council [2005],²⁷⁰ a case brought by a disabled adult with a degenerative condition

²⁶⁵ See for example *GS (India & Ors) v SSHO* [2015] EWCA Civ 40; *N v SSHD* [2005] UKHL 31 affirmed by ECtHR in *N v UK* [2008] 47 EHRR 39

²⁶⁶ *Ibid*

²⁶⁷ *Re OT* [2009] EWHC 633 (Fam)

²⁶⁸ A degenerative condition which is usually fatal within infancy. See <https://www.thelilyfoundation.org.uk/mi/mitochonDrial-disease/> for more detail, accessed 7th October 2017

²⁶⁹ *Re OT* [2009] EWHC 633 (Fam), para 97

²⁷⁰ *R (Burke) v The General Medical Council* [2005] EWCA 1003 at para.61, approving the dictum of Munby J. at first instance.

seeking clarification as to when it would be lawful for doctors to withdraw his artificial nutrition and hydration holding:

‘There is a very strong presumption in favour of taking all steps which will prolong life and save in exceptional circumstances or where the patient is dying the best interest of the patient will normally require such steps to be taken. In case of doubt, that doubt falls to be resolved in favour of the preservation of life but the obligation is not absolute. Important as the sanctity of life is, it may have to take second place to human dignity.’²⁷¹

In the Court’s view in Re OT the doctors in assessing the child’s best interests fulfilled the State’s obligation under Article 2.

The problem with this approach is however, that it does seem to be an imbalance between the level of scrutiny to which judges subject a parent’s assessment of a child’s best interests compared to the level of scrutiny undertaken ‘where responsible medical opinion is of the view that such treatment is in the best interests of the patient’.²⁷² While it is understandable why judges will want to defer to medics on purely medical matters, as Parker J herself went on to say ‘Best interests are not confined to best medical interests but embrace medical, social, emotional and welfare issues. The court is not tied to the clinical assessment of what is in the patient’s best interests and it will reach its own conclusion on the basis of careful consideration of the evidence before it.’²⁷³ The Courts perhaps need to explore much more how and why medics come to the conclusions they do with regard to a child’s best interests, which factors the medics have considered and in particular whether a clinical assessment is in fact based on clinical or non-clinical factors? The arguments made by counsel in Glass v UK already mentioned²⁷⁴ and Kennedy’s

²⁷¹ *Re OT* [2009] EWHC 633 (Fam), per Parker J

²⁷² *Ibid*, para 97

²⁷³ *Ibid*, para 98

²⁷⁴ *Glass v UK* [2003] ECHR Admissibility Decision no. 61827/00

arguments²⁷⁵ raised some twenty-five years earlier, seem pertinent here.

Research question two directly addresses this question by asking doctors about which factors they do consider and what weight they put on those factors, as will be seen in chapters four and five.²⁷⁶

The Commission of the ECtHR in *Glass v UK* dismissed as inadmissible the question of whether the doctors in that case had breached David's Article 2 rights, finding the application 'manifestly ill-founded'.²⁷⁷

David, who was born with hydrocephalus, is²⁷⁸ blind and has spastic quadriplegia and severe learning difficulties. He was described by Lord Woolf in the English Court of Appeal judgment as 'very seriously disabled but fortunately not terminally ill.'²⁷⁹ Scott Baker J, at first instance, also noted that David 'turned his head to sounds, laughs and smiles and registers his likes and dislikes by facial expressions'.²⁸⁰ David (the first applicant) and his mother Carol (the second applicant) complained to the ECtHR under Article 2 ECHR. Their complaint centred on the claim that following David's tonsillectomy²⁸¹ doctors 'put the first applicant's life at risk of premature termination'. In particular, Carol

²⁷⁵ Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

²⁷⁶ Chapter four, pp. 137-179, chapter five, 181-236

²⁷⁷ *Glass v UK* [2003] ECHR Admissibility Decision no. 61827/00. The ECHR held that the application was manifestly ill founded 'within the meaning of Article 35(3)', which states 'The Court shall declare inadmissible any individual application submitted under Article 34 which is considered incompatible with the provisions of the Convention or the protocols thereto, manifestly ill-founded, or an abuse of the right of application.'

²⁷⁸ 'Is' is used because, as far as it has been possible to ascertain through research David is still alive.

²⁷⁹ *Glass, R (on the application of) v Portsmouth Hospitals NHS Trust* [1999] EWCA Civ 1914 (21 July 1999), per Woolf L Master of the Rolls

²⁸⁰ *Glass, R (on the application of) v Portsmouth Hospitals NHS Trust* [1999] EWHC Admin 343 (22 April, 1999)

²⁸¹ To relieve upper airway obstruction.

objected to David being treated with diamorphine without her consent and to the doctors putting a 'Do Not Resuscitate' notice on David's medical notes without her knowledge or consent. **The case highlighted the importance of putting questions directly to paediatricians about any training or education in rights, law or ethics they had undertaken and, if any, the impact of this; questions explored with research questions three and four. As will be seen, commentators criticised the doctors seeing them as making quality of life judgments about David. This also inspired research question two, addressing the factors doctors use in their best interests decisions.** Due to its significance for this thesis, the case is explored here at some length.

In *Glass v UK* [2004], the ECtHR did not exclude the possibility

‘that acts and omissions of the authorities in the field of health care may in certain circumstances engage their responsibility under the positive limb of Article 2.’²⁸²

It was judged that this duty had been discharged by the UK, as adequate provision had been made by the government for securing high standards among health professionals and protection of lives of patients. In the ECtHR's view, an error of professional judgment (even if established) by a health professional is not sufficient to invoke Article 2. The court also considered the positive obligation to protect life through an effective domestic investigation, the procedural aspect of Article 2.²⁸³ It found this obligation effectively discharged by the GMC.²⁸⁴ The ECtHR refused to lift the veil, so to speak, on the doctors'

²⁸² *Glass v UK* [2003] ECHR Admissibility Decision no. 61827/00

²⁸³ The procedural aspect of Article 2 requires States to conduct an effective investigation into death. *Osman v UK* [1998] 23452/94 ECHR 101 (28 October 1998) established that the procedural aspect of Article 2 is triggered if there is a real and immediate threat to life. The investigation must be carried out by an independent body in public; it must be thorough and rigorous and must be capable of imputing responsibility for the death (*Hugh Jordan v UK*, 24726/94, [2001] ECHR 327 (4 May 2001))

²⁸⁴ The General Medical Council was established by the Medical Act 1983. It regulates UK doctors. Its primary duties are to protect and promote the health, safety and wellbeing of the public (s.1A (a)); promote and maintain public confidence in the medical profession (s.1A (b)); and promote and maintain proper professional standards and conduct for medical professionals (s.1A (c)).

decision-making for David, holding that they did not need to do so, as the GMC provided sufficient protection.

Commenting on the GMC's investigation into the doctors' conduct, the ECtHR held:

'According to the General Medical Council, the test for bringing disciplinary proceedings against the doctors was not satisfied on the evidence. It had asked itself in this connection whether the doctors put themselves in a reasonable position from which to arrive at the decision they did and whether the decision reached was so 'outrageous' that no reasonable competent doctor could have reached it'.²⁸⁵

The ECtHR judges saw this as allowing the UK a margin of appreciation, but this ruling can be criticised for the breadth of this margin. It is arguably unduly deferential to the medical profession in failing to lift the veil on either the doctors' or the GMC's decisions. As will be seen in chapter nine, the GMC's own statistics suggest it rarely investigates complaints brought by patients or their relatives.²⁸⁶ Arguably the ECtHR should have looked further and considered how and why the doctors decided to administer diamorphine, rather than holding as it did, that it was understandable that the domestic court did not look into the matter due to the factual dispute between the parties. The question of whether the ECtHR was being unduly deferential to the doctors arises, especially when compared with the detailed and forensic level of examination the ECtHR gave to examinations of the actions, thoughts and motivations of the security forces operating in Northern Ireland in cases such as *McShane v UK* [2002]²⁸⁷ and *McCann & Other v UK* [1995].²⁸⁸

²⁸⁵ *Glass v United Kingdom*, 61627/00 [2004] ECHR 103 (9 March 2004), at para 43

²⁸⁶ Chapter nine, para 3.1, p.367

²⁸⁷ *McShane v UK* [2002] 43290/98, ECHR 469 (European Court of Human Rights, May 2002. In this and *McCann v UK*, the ECtHR carried out an investigation of the actions and motivations of the security forces in Northern Ireland's 'shot to kill' policy in place in Northern Ireland.

²⁸⁸ *McCann & Others v UK* [1995] 18984/91 (European Court of Human Rights, September 27, 1995)

Although the GMC did not find David's doctors' conduct 'outrageous', the doctors treating David were criticised by other doctors. Indeed, a doctor who later treated David at Southampton General Hospital²⁸⁹ told the Sunday Telegraph of his horror at the decision made at St Mary's to let David die. He said:

'He was recovering and getting back to normal. I am astonished that diamorphine was used in a case like this with a child...I sometimes think that there is a different set of rules for the very disabled. Among some members of the profession, there is almost a presumption that the right to life doesn't apply to that group of patients.'²⁹⁰

Both the ECtHR judgment and the domestic judgments that preceded it, were strongly criticised by legal commentators, such as Huxtable and Forbes,²⁹¹ and Maclean²⁹² for their deference to the medical professionals.²⁹³ Indeed, some of the conclusions drawn by the Strasbourg judges seem to do no more than defer to the St Mary's doctors. As Huxtable and Forbes²⁹⁴ and others²⁹⁵ questioned the extent to which 'quality of life reasoning crept into their [the doctors']

²⁸⁹ Portsmouth NHS Trust the health trust responsible for St Mary's hospital decided it would not be possible to continue treating David following clear break down of trust between the doctors there and his mother. Arrangements were made for David to have all future hospital care at Southampton General Hospital.

²⁹⁰ Hall, C, (2000) *Rough Justice*, The Sunday Telegraph, 16th July, 2000 p.24

²⁹¹ Huxtable, R, Forbes, K, (2004) 'Glass v UK: Maternal Instinct v Medical Opinion', *Child and Family Law Quarterly*, vol.16, No.3, pp.339-354

²⁹² Maclean, AR, (2000) 'The Human Rights Act 1998 and the Individual's Right to Treatment,' *Medical Law International*, vol 4, Issue 3-4, pp 245-276

²⁹³ For example, in *Glass v United Kingdom* [2004] 61627/00 ECHR 103 (9 March 2004), the Court held 'the applicants' complaint under Article 2 amount to in effect a criticism of the doctors' clinical judgment.... However, it is not the function under Article 2 to gainsay the doctor's assessment of the first applicant's condition at the time'

²⁹⁴ Huxtable, R, Forbes, K, (2004) 'Glass v UK: Maternal Instinct v Medical Opinion', *Child and Family Law Quarterly*, vol.16, No.3, pp.339-354, p. 346

²⁹⁵ See for example: Maclean, AR, (2000) 'The Human Rights Act 1998 and the Individual's Right to Treatment,' *Medical Law International*, vol. 4, Issue 3-4, pp 245-276

decision-making'.²⁹⁶ Maclean puts it even more strongly; 'if he had not been so severely handicapped (sic) would the doctors have felt that it would be best to treat him palliatively and allow him to die?'²⁹⁷ Maclean, who was himself a medical doctor before becoming a legal academic, continues:

'if a non-handicapped child developed septicaemia following a routine tonsillectomy the doctors would pull out all the stops to save his life. There would certainly be no question about giving the child antibiotics....Thus the doctors have altered their management because they perceived David's quality of life to be not worth saving'.²⁹⁸

The concerns raised by commentators on the Glass litigation as to the appropriateness of quality of life judgments being included in best interest decisions for disabled children, was another way in which this case directly influenced the shape of this thesis, leading as it did with research question two to doctors being asked about the use of quality of life and other factors in their difficult decisions for disabled children. What the doctors said about these factors is discussed in depth in chapter five.²⁹⁹

7.2 Article 8 ECHR

In *Glass v UK* [2004]³⁰⁰ the ECtHR judged both David's and his mother's Article 8³⁰¹ right to respect for private and family life to have been breached by the doctors' decision to impose treatment on David in defiance of his mother's objections. In particular, David's right to physical integrity was breached.³⁰²

²⁹⁶ Huxtable, R, Forbes, K, (2004) 'Glass v UK: Maternal Instinct v Medical Opinion', *Child and Family Law Quarterly*, vol.16, No.3, pp.339-354, page 346

²⁹⁷ Maclean, AR, (2000) 'The Human Rights Act 1998 and the Individual's Right to Treatment,' *Medical Law International*, vol 4, Issue 3-4, pp 245-276, at p.268

²⁹⁸ Maclean, AR, (2000) 'The Human Rights Act 1998 and the Individual's Right to Treatment,' *Medical Law International*, vol 4, Issue 3-4, pp 245-276, at p. 268

²⁹⁹ Chapter five, pp.181-236

³⁰⁰ *Glass v United Kingdom* [2004], 61627/00 ECHR 103 (9 March 2004)

³⁰² *Glass v United Kingdom*, [2004] 61627/00 ECHR 103 (9 March 2004) at para 70.

The court was particularly critical of the hospital's failure to apply for an emergency court order when his mother's firm objection to the administration of diamorphine became clear. While accepting that the doctors in their clinical judgment were acting in David's best interests,³⁰³ the ECtHR highlighted the fact that doctors had been in discussions with David's mother for a number of months beforehand about the treatment David should receive, should he deteriorate.³⁰⁴ They had the time to secure the presence of a police officer,³⁰⁵ but chose not to make an emergency application to court.

The ECtHR also refers to the doctors' 'rather insensitive attempts to overcome [David mother's] opposition.'³⁰⁶ The judgment suggests that the hospital had firm views about the role of the Court, for example, they asserted that they did not apply to court because:

'the court could have offered no remedy that could have benefited [David's mother] in the circumstances of the case. In particular, the High Court would not have ordered the doctors to provide treatment that they did not consider clinically appropriate and would not have regarded the second applicant's view as determinative if they conflicted seriously with the doctor's view of the first applicant's best interests'.³⁰⁷

There is plentiful, strong dicta in support of the hospital's assertion that the court would not order doctors to treat in a manner contrary to their clinical judgment, for example Balcombe LJ in the aforementioned *Re J* [1991].³⁰⁸ However, the courts have repeatedly stressed that cases are dependent on their particular

The ECtHR awarded David compensation of 10,000 euros plus costs.

³⁰³ *Glass v United Kingdom* [2004], 61627/00 ECHR 103 (9 March 2004), para 77

³⁰⁴ *Ibid*, para 78

³⁰⁵ *Ibid*, para 81

³⁰⁶ *Ibid*, para 82

³⁰⁷ *Ibid*, para 66

³⁰⁸ *Re J (A Minor) (Wardship: Medical Treatment)* [1991] [1991] Fam. 33; [1991] 2 W.L.R. 140, per Balcombe LJ

facts³⁰⁹ and indeed, in 1997 the year prior to the events in *Glass*,³¹⁰ the Court of Appeal in *Re T* [1997]³¹¹ did, going against the opinion of the doctors, find in keeping with the parents' wishes that a child should not have an operation, doctors believed to be in the child's best interests. Of course, in *Re T* the Court of Appeal was not ordering the doctors to act, but rather holding that they should not act. In a later case of *MB* [2006]³¹² the Court also agreed with the parents' assessment of their child's best interests, against the unanimous opinion of all the medical experts, declining to make the order sought by the medical team that MB's ventilation should be discontinued. Hospitals deciding not to apply to court on the assumption that the court would be obliged to agree with the doctors' determination of a child's best interests seems to make a nonsense of the purpose of best interest applications and the well-established principle that it is not for the doctors nor a child's parents to determine a child's best interests, but for the court.³¹³ Indeed, this seems to be the viewpoint of the ECtHR judges in *Glass v UK*, holding as they did, that the trust breach David and his mother's right to a family life pursuant to Article 8, by failing to apply to court for a best interests determination.³¹⁴ The hospital were, however, perhaps correct to identify a conflict between a court respecting a doctors' clinical autonomy and acting in a child's best interests if the court saw this as something different from the doctor's intended action. **Research question four in this thesis addresses whether the doctors in this study do apply to court when they encounter disagreements as to a child's best interests and the doctors' thoughts and feelings about applications to court, as will**

³⁰⁹ *An NHS Trust v MB* [2006] EWHC 507 (Fam), para 16 (ix), per Holman J, cited with approval in *Great Ormond Street Hospital v Constance Yates, Chris Gard, Charles Gard*, [2017] EWHC 972 (Fam) para 39, per Francis J

³¹¹ *T (A Minor), Re* [1996] EWCA Civ 1313 (24 October 1996) (1997)

³¹² *An NHS Trust v MB* [2006] EWHC 507 (Fam)

³¹³ *Re B (A Minor) (Wardship, Medical Treatment)* [1981] CA, WLR 1421 and *Re J (A Minor) (Wardship: Medical Treatment)* [1991] [1991] Fam. 33, [1991] 2 W.L.R. 140, per Lord Donaldson

³¹⁴ *Glass v United Kingdom* [2004] (61827/00) 1 F.L.R 1019

be seen in chapters eight and nine. This issue also arises earlier in chapter six of this thesis in the context of how doctors balance respect for each other's clinical autonomy with disagreements as to a child's best interests.³¹⁵

7.3 Article 14 ECHR

Earlier discussion of Article 2 in relation to the Glass litigation considered the criticism of the doctors by commentators such as Huxtable and Forbes³¹⁶ and Maclean³¹⁷ and others.³¹⁸ Commentators particularly expressed their concern that doctors discriminated against David and made value judgments about his quality life. The ECtHR clearly did not think so, rejecting as they did David's application pursuant to Article 14 ECHR.³¹⁹ It held:

‘there is no evidence whatsoever on which to base an arguable complaint that the first applicant was a victim of discrimination on account of the fact that he was severely handicapped’.³²⁰

As English³²¹ in her commentary on the case argues, evidence of discriminatory practice in such cases is almost by its nature unforthcoming, making proving

³¹⁵ Chapter six. Para 7.1-7.2, pp. 253-267

³¹⁶ Huxtable, R, Forbes, K, (2004) ‘Glass v UK: Maternal Instinct v Medical Opinion’, *Child and Family Law Quarterly*, vol.16, No.3, pp.339-354, at p.346

³¹⁷ Maclean, AR, (2000) ‘The Human Rights Act 1998 and the Individual's Right to Treatment,’ *Medical Law International*, vol 4, Issue 3-4, pp 245-276 at page 268

³¹⁸ For example, the Southampton General consultant: Hall, C, (2000) *Rough Justice*, The Sunday Telegraph, 16th July, 2000 p.24

³¹⁹ Article 14 ECHR ‘*The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any grounds such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.*’

³²⁰ *Glass v UK* [2003] ECHR, Admissibility Decision, (16 March 2003)

³²¹ English, R, (2007) *Human Rights Update: Glass v UK*, One Crown Office Row, London, <http://www.humanrights.org.uk/814/> accessed 3 December 2015

discrimination extremely difficult. However, when even, as was seen,³²² other doctors involved in David's care, expressed their shock at the treatment David received and believed David was discriminated against, suggesting the question merits greater level of investigation than that expended by the ECtHR. With the Commission of the ECtHR rejecting the possibility that David was a victim of discrimination,³²³ it does seem that the courts lag behind civil society, the NHS, UK government and the UN in acknowledging the fact that disabled children and adults can and do face discrimination in healthcare in the UK, as will now be explored.

8. Investigations and reports acknowledge poor care

During the later years of this review, several government and voluntary sector reports found 'discrimination, negative attitudes, segregation, stigmatization and other poor service provision'³²⁴ for disabled people within the NHS. 2001 saw the publication of the Final Report of the Royal Infirmary Inquiry ('Bristol')³²⁵ chaired by, the by now, Sir Ian Kennedy. It investigated the treatment of children receiving complex cardiac care at the Bristol Royal Infirmary between 1984 and 1995. Bristol identified the culture amongst the medical professionals as one of the factors leading to the poor treatment some children received. It referred to the 'club culture' among doctors.³²⁶ Bristol made 198 recommendations to improve paediatric care across the UK. The long-term

³²² Chapter two, para 7.1, p.70

³²³ *Glass v UK* [2003] ECHR, Admissibility Decision, (16 March 2003), para 5

³²⁴ Basnett, I, (2001) 'Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467

³²⁵ The Bristol Royal Infirmary Inquiry (2001), *The Inquiry into the management of care of children receiving complex heart surgery at the Bristol Royal Infirmary, Final Report*, Bristol Royal Infirmary Inquiry

³²⁶ *Ibid*, paragraph 8 of Synopsis

impact of Bristol is questionable in light of the fact a further inquiry into the same service was set up by the Medical Director of NHS England in 2016.³²⁷

The years immediately following the Glass litigation saw a spate of reports, suggesting the Commission of the ECtHR's confident rejection of the possibility that the doctors treating David could have discriminated against him, was perhaps overly optimistic. A 2006 investigation by the Disability Rights Commission ('DRC') found the response from government and NHS in England and Wales to the major health inequalities faced by people with learning disabilities inadequate.³²⁸ Significantly for this thesis, the DRC's investigation found that parents of children with the most complex impairments experienced the greatest difficulties. In similar vein, a 2008 Healthcare Commission investigation found disabled children with complex health needs 'do not always get the attention and care from healthcare services that they need.'³²⁹

Also in 2008, the Every Disabled Child Matters Campaign reported:

'Disabled Children experience unequal access to health promotion programmes, universal health services such as GPs, dentists and emergency care settings, as well as specialist and appropriate palliative care services.'³³⁰

³²⁷ Grey, E, Kennedy, I (2016) *The Report of the Independent Review of Children's Cardiac Services in Bristol*; June 2016; www.thebristolreview.co.uk/Bristol-Review--FINAL-REPORT.pdf; accessed 19 December 2016

³²⁸ Disability Rights Commission (2006) *Equal Treatment Closing the Gap*, DRC, London, available on line at <http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=187482>, accessed 1st December 2010

³²⁹ Healthcare Commission (2008) *State of Healthcare*, Healthcare Commission (now defunct), p11 available on line at http://webarchive.nationalarchives.gov.uk/20100611090857/http://www.cqc.org.uk/_db/_documents/State_of_Healthcare_2008.pdf, accessed 1 December 2010

³³⁰ Franklin L, (2009) *Disabled Children and Health*, National Children's Bureau, London, p5, https://www.pmguk.co.uk/data/page_files/publications%20and%20reports/2009/R.DisabledchildrenhealthEveryChildMatters.pdf, accessed 8 October 2017

The same year, as was seen earlier³³¹ the UNCRC Committee raised its concerns in its Concluding Observations on the UK, that disabled children *continue* to face significant difficulties in realising their rights to healthcare.³³²

In March 2009, the Parliamentary and Health Service Ombudsman ('PHSO') published a report following investigations in the treatment of six adults with learning disabilities. In the words of the PHSO:

'The investigation reports illustrate some significant and distressing failures in service across both health and social care. They show the devastating impact of organisational behaviour, which does not adapt to individual needs, or even consistently follow procedures designed to maintain a basic quality of service for everyone. They identify a lack of leadership and a failure to understand the law in relation to disability discrimination and human rights. This led to situations in which people with learning disabilities were treated less favourably than others, resulting in prolonged suffering and inappropriate care.'³³³

Kennedy appeared once again when commissioned by the Department of Health to write the 2010 report 'Getting It Right for Children and Young People',³³⁴ on the healthcare of children and young people. This cites the hostility parents can face when trying to secure healthcare for their disabled child.³³⁵ The same year the Independent Inquiry chaired by Sir Jonathan Michael in 2010 reported 'people with learning disabilities receive less effective

³³¹ Chapter two, para 4, p.47

³³² United Nations Convention on the Rights of the Child (2008) *Committee on the Rights of the Child; Consideration of reports submitted by state parties under Article 44 of the Convention; third and fourth periodic reports of States parties due in 2007 United Kingdom of Great Britain and Northern Ireland*, CRC/GBR/4, United Nations, Geneva, paras 64-68, para 52 (B)

³³³ Parliamentary and Health Service Ombudsman, (2009), *Six lives: the provision of public services to people with learning disabilities*, PHSO, London, p. 7

³³⁴ Kennedy, I, (2010) *Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs*, Department of Health, London, <https://www.gov.uk/government/publications/getting-it-right-for-children-and-young-people-overcoming-cultural-barriers-in-the-nhs-so-as-to-meet-their-needs>, accessed 8th October 2017

³³⁵ *Ibid*, para 3.9, page 28

care than they are entitled to receive'.³³⁶ This was followed by Mencap's 2013 Death by Indifference report into the seventy-four deaths of cognitively disabled adults and children. It found institutional discrimination within the NHS.³³⁷ Reports into institutionalised discrimination against disabled children and adults continue to be published on a regular basis,³³⁸ suggesting perhaps for many severely disabled children and young people rights legislation has had little or no impact on the ease with which they access healthcare.

A recurrent theme in the cases and the commentaries is the lack of impact of the HRA and ECHR. The number of inquiries into the poor treatment of disabled children and adults at one level suggests that the HRA is having an impact in that the rights of disabled children and adults are being taken more seriously resulting in the investigations, which would not have happened in an earlier era. However, the need for the investigations and the high number of disabled people involved in some of the studies, suggests that at front line level, rights are not always being respected. As Laurie says '[T]he advent of the Human Rights Act has done little to change the established orthodoxy.'³³⁹ **One questions the Glass litigation and these multiple inquiries prompted in this thesis, is the question, as**

³³⁶ Michael, J, (2008) *Healthcare for all*, Learning Disabilities Observatory, London, http://webarchive.nationalarchives.gov.uk/20130105064756/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106126.pdf, accessed 8th October 2017

³³⁷ Mencap (2012) *Death by Indifference: 74 deaths and counting*, Mencap, London <https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf>, accessed 8th October 2017

³³⁸ More recent examples includes Francis (2013), *Report of NHS Mid Staffordshire NHS Foundation Trust Public Inquiry*, The Stationery Office, Mazar, (2015) *Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015*, NHS England <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf>, accessed 8 October 2017 and Care Quality Commission, (2016), *'Learning candour and accountability'* CQC a report which reviews the way the NHS investigates patient's deaths, including the deaths of disabled children, in England.

³³⁹ Laurie G (2006) 'The Autonomy of Others: Reflections on the Rise and Rise of Patient Choice in Contemporary Medical law' chapter 9, in Mclean, SAM, *First Do No Harm, Law Ethics and Healthcare*, Ashgate, Farnham, pp. 135-136

part of addressing research question four, put directly to the doctors in the thesis survey: ‘Are a child’s human rights a factor you consciously consider’?³⁴⁰

This review of the legal and ethical landscape, so far, seems to suggest, that little changed in the treatment of disabled children generally or in the way best interest decisions were approached for disabled children in particular, as a result of the HRA or the national and international child rights legislation that preceded it. This chapter now goes on to consider whether the introduction of United Nations Convention on the Rights of Persons with Disabilities (‘UNCRPD’)³⁴¹ had any more of an impact on the lives of the UK’s disabled children than the earlier legislation.

9. **More rights? United Nations Convention on the Rights of Persons with Disabilities**

The UNCRPD³⁴² was adopted by the General Assembly of the UN on 13 December 2006 and was open for signature on 30 March 2007. The UK ratified the UNCRPD on 8 June 2009 and the Optional Protocols, which empowers individuals to make complaints directly to the Committee of the UNCRPD and the Committee to conduct inquiries within the UK on 7 August 2009.

Article 7 UNCRPD³⁴³ deals expressly with the rights of disabled children. It is

³⁴⁰ Chapter nine, para 4, p. 378

³⁴¹ United Nation Convention on the Rights of Persons with Disabilities, adopted by the General Assembly of the United Nations on 13 December 2006 and was open for signature on 30 March 2007. The UK ratified the UNCRPD on 8 June 2009

³⁴² Ibid

³⁴³ Article 7 UNCRPD - Children with disabilities

‘1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

noteworthy that the wording used in Article 7 is much more affirmative than that used in Article 23 UNCRC, the article of the UNCRC dealing expressly with disabled children's rights. It is also of note, that just as all the provisions of the UNCRC apply equally to disabled children and not just Article 23, so to do all the provisions of UNCRPD apply to disabled children. As Alkazi³⁴⁴ reports, discussion took place during the drafting process as to whether it was necessary to have an article in the UNCRPD dealing expressly with the rights of children, particularly as the UNCRC existed and included Article 23. The drafters, however, agreed to affirm that all UNCRPD rights apply to children. They recognised that states tend to only consider disabled children's rights in relation to Article 23 UNCRC, rather than in relation to the whole UNCRC, as they should.³⁴⁵ Perhaps drawing from this negative UNCRC experience, the UNCRPD makes further reference to children in other articles. However, there is still the risk that State Parties overlook the position of children where express reference to them is not made and only address the rights of children where they are expressly mentioned in the UNCRPD.

The UNCRPD does not introduce any new rights. It identifies the rights of disabled persons and the obligations on State parties to promote, protect and ensure existing rights. Like the UNCRC and other international human rights conventions, the UNCRPD, introduces an international committee of experts to monitor State Parties implementation of the Convention. A Conference of State Parties is also established to consider matters regarding implementation.

2. *In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.*

3. *States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right.'*

³⁴⁴ Alkazi, R (2011) 'Disability at the UN', in Dobhai, H, *Writing on Human Rights, Law and Society in India*, Socio-Legal Information Centre, Human Rights Law Network, Delhi

³⁴⁵ Ibid

One question that arises, is the extent to which the UNCRPD can be used by severely disabled children, particularly considering the barriers already exposed in the various investigations mentioned, to disabled people generally having their rights within healthcare recognised. The fear is that just as the position of disabled children have been largely overlooked in the UK's considerations of the UNCRC, likewise the position of disabled children is again at risk of being overlooked. The first Concluding Observations of the Committee of the UNCRPD³⁴⁶ published in 2017 suggests this fear is a valid one. Children are mentioned in relation to Article 7, but otherwise only expressly mentioned when consideration is given to just a limited number of the Articles such as, Article 24 (education) and Article 16 (protection from exploitation and abuse). Talking about access to healthcare, the Committee finds that 'systematic, physical, **attitudinal** and/or communicative' (emphasis added) barriers exist in the UK³⁴⁷ which prevent disabled people accessing mainstream healthcare, but children are not expressly mentioned here or at all in relation to the right to healthcare.

There is little evidence then that the UNCRPD had any greater success in making disabled children's rights in healthcare paramount than the domestic or international legislation that preceded it. As was seen however, the UNCRPD committee mentioned attitudes as one of the barriers to healthcare for disabled people generally in the UK. This chapter now turns to consider literature which examines the impact of professional attitudes on disabled people's healthcare. As was discussed in chapter one,³⁴⁸ children rarely feature in this debate,³⁴⁹ so literature relating largely to disabled adults is now explored.

³⁴⁶ UNCRPD, (2017) *Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland*, CRPD/C/GBR/CO/1, United Nations, Geneva

³⁴⁷ Ibid, para 54

³⁴⁸ Chapter one, para 2.2, p.3

³⁴⁹ Coker, M, Davis, JM (2000) 'Disabled Children (Still) Invisible Under the Law', in Cooper, J, *Law Rights and Disability*, Jessica Kingsley Publishers, London

10. Impact of medical professionals' attitudes on treatment of disabled people

There has been much research on the attitudes of healthcare professionals towards disabled adults, both here and in other jurisdictions.³⁵⁰

Byron et al suggest that the consensus of studies find '[h]ealth professionals especially doctors are perceived as insensitive and patronising'.³⁵¹ Hordon³⁵² and Mitchell et al³⁵³ did find improvements in attitudes towards disabled patients in medical students over the duration of their training, but unfortunately the students were not followed up long term. Negative attitudes do seem prevalent. Indeed, a review of studies since Kennedy's Astor lecture, suggests little change in attitudes despite all the legislation and professional guidance discussed in this chapter. French conducted a study in 1988, looking at health and social care professionals' attitudes towards twenty-four individuals with

³⁵⁰ Examples include: French S, (1988) Experience of disabled health and caring professionals, *Sociology of Health and Illness*, vol.10 Issue f2; pp.170-188; Duckworth SC, (1988), The effects of medical education on the attitudes of medical students towards disabled people, *Medical Education*, vol 22, Issue 6, pp.501-505; Gerhart K, Koziol-McLain J, Lowenstein S et al, (1994) Quality of life following spinal cord injury: Knowledge and attitudes of emergency care professionals, *Annals of Emergency Medicine*, vol 23, Issue 4, pp.807-812; Fitzsimmons J & Barr O, (1997), A review of the reported attitudes of health and social care professionals towards people with learning disabilities: implications for education & further research, *Journal of Intellectual Disability*, vol. 1, Number 2, pp.57-64; Basnett, I, (2001)' Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467; Martin, HL, Powell, MM, Reid ,SM et al (2005) Cerebral Palsy what do medical students know and believe?, *Journal of Paediatrics & Child Health* vol.41, Issue 1-2, 2005, pp. 43-47; Rose, N, Kent, S, et al (2010) Health professional's attitudes and emotions towards working with adults with intellectual disability and mental ill health, *Journal of Intellectual Disability*, 56, 854–864

³⁵¹ Byron, M, Cockshott, Z, Brownett, H, Ramkalwan T (2005) What does 'disability' mean for medical students? An exploration of the words medical students associate with the term 'disability, *Medical Education*, 39, 176-183, Blackwell Publishing Ltd

³⁵² Hordon, L.D (1993) The effect of Medical Training on Attitudes to Disabled People, *British Journal of Rheumatology*, 32: 151

³⁵³ Mitchell, KR, Hayes, M, Gordon, J & Wallis, B, (1984), An Investigation of the Attitudes of Medical Students to Physically Disabled People, *Medical Education*, 18: 21-23

'substantial' impairment wanting to enter the health and social care professions. French does not define 'substantial' but does list the participants' impairments. They include, for example, three participants with cerebral palsy; one with epilepsy, four with lower limb amputations and one with tetraplegia. However, most of the conditions listed cover a wide spectrum of possible impairment so this list is of limited value in clarifying French's definition. As the individuals were planning to enter health and social care professions it seems their impairments, when compared with the children in this study, are likely to have been minor. Moreover, the study seems to cover only individuals with physical and not cognitive impairments. Repeated investigations in recent years have shown people with cognitive impairments (or assumed by health professionals to have cognitive impairments), experience the most negative attitudes from health professionals.³⁵⁴ French found, however, that '...while most respondents reported either positive or neutral attitudes from colleagues, a sizeable minority experienced negative attitudes'³⁵⁵ from health professionals. In contrast, the study found 'Negative attitudes from patients and clients, 'exceptionally rare.'³⁵⁶ The French study therefore suggests that, at that time, health professionals' attitudes were worse than those of non-health professionals.

There are factors, which make it difficult to generalise from French's study. For example, whether the health professionals were particularly hostile to disabled people as colleagues or to disabled people in general. Also, the positive attitudes of clients and patients may not be typical of the general population. The nature of their relationship with the disabled person as their health

³⁵⁴ See for example: Mencap (2012) *Death by Indifference: 74 deaths and counting*, Mencap, London <https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf>, accessed 8 October 2017 and Mazar, (2015) *Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015*, NHS England, <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf>, accessed 8 October 2017

³⁵⁵ French S (1988) Experience of disabled health and caring professionals, *Sociology of Health and Illness*, vol.10 Issue f2. pp.170-188, at p.170

³⁵⁶ Ibid

professional may have influenced their attitudes. There may have also been factors about the patients which led to unusually positive attitudes, for example, some may be disabled individuals themselves. A comparison can be made with a study by Duckworth,³⁵⁷ published the same year, which compared the attitudes of Southampton medical students and junior doctors with the general population. Again, this study was only concerned with attitudes towards people with physical impairments. Using a questionnaire developed by Yuker & Block,³⁵⁸ Duckworth assessed the difference in attitudes between first and fourth year medical students; Senior House Officers (SHOs)³⁵⁹ and a control group of the general public. Duckworth found no significant difference between the attitudes of the general public, the medical students and the SHOs. However, he did find that more 4th year students and SHOs agreed with the statement 'Disabled people cause more problems to doctors than non-disabled people'.³⁶⁰ He also found that within each group there was a sub-population with significantly more negative attitudes. This does tend to suggest that at the time of the study, attitudes deteriorated as medical students progressed through their training and qualify. Indeed, it may be significant that students often have patient contact for the first time in their 4th year of training, potentially suggesting that treating and interacting disabled people impacted negatively on the doctors' attitudes. Although old, these two studies are of interest to this thesis as, as will be seen in chapter four,³⁶¹ they were conducted at the time when the majority of the doctors in this study were in training.

³⁵⁷ Duckworth, SC, (1988), The effects of medical education on the attitudes of medical students towards disabled people, *Medical Education*, vol.22, Issue 6, pp.501-505

³⁵⁸ Yuker, HE, Block, J. R, Young, JH, (1966) *The measurement of attitude toward disabled persons*, Human Resources Study No. 7, Human Resources Center, Albertson

³⁵⁹ Junior doctors in their first years of training. The term 'Foundation Doctor' has now replaced the term Senior House Doctor in the UK

³⁶⁰ Duckworth SC, (1988) The effects of medical education on the attitudes of medical students towards disabled people, *Medical Education*, vol. 22, Issue 6, pp.501-505 at p. 501

³⁶¹ Chapter four, para 4.5, pp.157-158

The following decade, in 1994 Gerhart et al³⁶² published a study in the USA, comparing the attitudes towards severe physical impairment of health professionals working in a Denver emergency department, with the attitudes of individuals living with severe physical impairment. The disabled participants all had high-level quadriplegia, resulting in paralysis usually caused during accidents.³⁶³

Gerhart et al compared the answers of 233 health professionals with 128 disabled individuals. They report that 41% of the health professionals thought the resuscitation attempts in such cases were too aggressive. Further, 22% of the health professionals said they would not want treatment at all to survive in such circumstances and a further 23% said they would only want pain relief. While only 18% of the health professionals said they thought they would be glad to be alive after sustaining such an injury, 92% of the individuals with the injury reported they were glad to be alive. Also, while only 17% of the health professionals said they thought the quality of life of individuals with such impairment would be average or better than average, 86% of the actual group reported their quality of life to be average or above average. A 1989 study by Whiteneck³⁶⁴ reported similar findings for individuals with a similar level of impairment, but also in addition needing long-term ventilation. Although just two studies, these do suggest significant differences in how disabled people with very severe physical impairments view the quality of their own lives, compared to health professionals' perceptions. Moreover, these were individuals who had previously been non-disabled so could make a direct comparison between their lives before and after they sustained their injuries. Gerhart et al acknowledged some limitations in their study, for example, the survey measured only doctors'

³⁶² Gerhart, K, Koziol-McLain, J, Lowenstein, S et al (1994) Quality of life following spinal cord injury: Knowledge and attitudes of emergency care professionals, *Annals of Emergency Medicine*, vol. 23, Issue 4, 1994, pp.807-812

³⁶³ Ibid, p.808

³⁶⁴ Whiteneck, G, (1989) Long-term outlook for persons with high quadriplegia, in Whiteneck G, Adler C, Carter RE et al (eds) *The Management of High Quadriplegia*, Demos Publications, New York

attitudes in hypothetical not actual situations. They also acknowledged that they had no information on the practitioners' length of service; their ethnicity and their religious beliefs, all of which Gerhart et al acknowledge could impact on attitudes.³⁶⁵ Despite these limitations Gerhart et al conclude 'the existence of any underlying 'better off dead' assumptions in emergency care providers, may have a significant impact on the delivery of care.'³⁶⁶

This study was influential in the questionnaire design in this thesis, ensuring questions were asked of the doctors about their length of service, ethnicity, gender, religious beliefs and other factors. To answer research question two, doctors were asked about the impact of a child's impairment on their decisions and the doctors responses, as will be seen in chapter five³⁶⁷ were mapped against key personal and professional characteristics for each doctor to see if any there was any suggestion that doctors with particular characteristics behave in a particular way.

The new millennium saw a spate of new studies of medical students' attitudes towards disabled patients. This in itself was perhaps a positive sign, as it suggested a growing recognition that medics' attitudes towards disabled patients were important and worthy of academic study. These studies also tended to be done to assess the impact of disability rights/awareness training on medical students, at a time when 'disability' was beginning to feature on the medical curriculum. A 1990 study by Marshall & Haines³⁶⁸ had found that 25% of UK medical schools had no structured teaching in any department about

³⁶⁵ Gerhart, K, Koziol-McLain, J, Lowenstein, S et al (1994) Quality of life following spinal cord injury: Knowledge and attitudes of emergency care professionals, *Annals of Emergency Medicine*, vol. 23, Issue 4, 1994, pp.807-812, p.811

³⁶⁶ Ibid

³⁶⁷ Chapter five, para 6, pp. 226-234

³⁶⁸ Marshall, J, Haines, A (1990) Survey of the teaching of disability and rehabilitation to medical undergraduates in the UK, *Medical Education*, 24, pp. 528-530

disability.³⁶⁹ What education there was tended to take a very biomedical approach, with it seems, at least some of the medical student taking the subject less than seriously. As Basnett, whose paper is considered in more detail later,³⁷⁰ described in 2001:

‘My medical training was traditional and typical- biomedical and hospital dominated. The disabled people I came into contact with were usually ill or institutionalised. I was taught about body systems and their failures, but rarely about the interaction between our bodies, the environment and society....I had one memorable afternoon... We ran around with empty wheelchairs, ‘learning about obstacles’. Many of us used it as an opportunity to play bumper cars’.³⁷¹

As late as 2013 there was no consensus across UK medical schools as to how health inequalities, including disability should be taught at undergraduate level.³⁷² The example of best practice Williamson & Ayres gave in their proposed undergraduate core curriculum, also suggests very little of the medical students’ six years undergraduate study be spent on understanding disability:

‘A session on the ‘nature of culture’ which is further explored within sociology teaching. In Year 2 there are symposia on both physical disability and mental illness.’³⁷³

Indeed, it is noteworthy that learning disabilities are not mentioned at all.

³⁶⁹ Ibid, p. 529

³⁷⁰ Chapter two, para 10, pp.89-90

³⁷¹ Basnett, I, (2001) ‘Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People’, in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467, p.451

³⁷² Williamson, A E. Ayres, R. (2013) *A core curriculum for learning about health inequalities in UK undergraduate medicine*, RCGP, London

³⁷³ Williamson, A E. Ayres, R. (2013) *A core curriculum for learning about health inequalities in UK undergraduate medicine*, RCGP, London, p.6

Martin et al's³⁷⁴ 2005 Australian study did unusually consider medical students' attitudes towards children living with cerebral palsy. It found that 54 medical students had very poor knowledge of cerebral palsy, leading to negative attitudes, when in the penultimate year of their undergraduate training. Whilst recognising that medical students could not be made aware of all conditions; the authors point out that cerebral palsy 'is the commonest cause of childhood physical disability.'³⁷⁵ The study found that nearly half the students' responses suggested that they believed a child with cerebral palsy would be better off dead.³⁷⁶ As the authors rightly comment: '[t]hese views are potentially damaging for the care of persons with cerebral palsy. A doctor who does not value the life of their patient as much as other people may be less likely to advocate for their rights'.³⁷⁷ The Martin et al study seems to be in keeping with the findings of other studies into the health professionals' attitudes towards disabled adults, suggesting that doctors tend to assume disabled people have such a poor quality of life that their lives are not worth saving.

Tracey & Iacono's³⁷⁸ 2008 Australian study took a radical approach for its time, of medical students being taught by teachers with learning disabilities. 128 medical students completed an attitude scale³⁷⁹ at the beginning and end of the study.³⁸⁰ The authors report their study show the students were significantly

³⁷⁴ Martin, HI, Rowell, MM, Reid, SM, Marks, MK, Reddihough, D (2005) Cerebral palsy: What do medical students know and believe?' *J. Paediatric Child Health*, 41, pp. 43-47

³⁷⁵ Ibid, p. 43

³⁷⁶ Ibid, p. 46

³⁷⁷ Ibid, p. 46

³⁷⁸ Tracy, J, Iacono, T (2008) People with developmental disabilities teaching medical students – Does it make a difference? *Journal of Intellectual and Developmental Disability*, Vol.33 (4), pp. 345-348

³⁷⁹ Gething, I, (1994) The interaction with Disabled Person Scale, *Journal of Social Behaviour and Personality*, 9, pp. 23-42

³⁸⁰ Tracy, J, Iacono, T (2008) People with developmental disabilities teaching medical students – Does it make a difference? *Journal of Intellectual and Developmental Disability*, Vol.33 (4), pp. 345-348, p. 345

more comfortable about interacting with people with learning disabilities after their tutorials than before. Discomfort in interacting with certain patients will certainly impact on the care those patients receive. Indeed, Tracy & Iacono cite³⁸¹ Gill et al recommend better communication between general practitioners and patients with learning impairments as a means of improving patients' healthcare.³⁸² Byron et al³⁸³ similarly found in their 2005 study, the attitudes of 381 Bristol medical students changed from using predominantly negative and patronising language about disabled people to positive language after disability awareness training.

Basnett who described³⁸⁴ his training in disability in the early 1980s, severed his cervical spinal cord playing rugby, whilst working as a doctor. His perspective as a newly disabled medic is an illuminating one. Basnett is in the unusual position of being able to speak both from the perspective of a non-disabled doctor and following his injury, as a disabled patient with a significant impairment. This makes him particularly well placed to put the perceptions of a disabled person into the context of the training and culture of the medical profession.

Basnett's paper, as mentioned in chapter one, was highly influential in the design of this thesis. **It influenced research questions two and three; asking doctors about the factors they consider when making best interest decisions; their education and training and the impact of this on their attitudes and values. Basnett also articulated the importance of the**

³⁸¹ Ibid, p.346

³⁸² Gill, F, Stenfert Kroesa B, Rose J (2002) General Practitioners attitudes to patients who have learning disabilities, *Psychological Medicine* 32 pp.1445-1455

³⁸³ Byron, M, Cockshott, Z, Brownett, H, Ramkalwan T (2005) What does 'disability' mean for medical students? An exploration of the words medical students associate with the term 'disability', *Medical Education*, 39, 176-183, Blackwell Publishing Ltd

³⁸⁴ Basnett, I, (2001) 'Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467

interactions between health professionals in creating those attitudes and values, something discussed with the doctors in this thesis. Likewise, it influenced the inclusion of a question about doctors' personal experience of disability, if any, be it their own, or a close relative.

Basnett explained very eloquently the dramatic impact his own impairment on his attitude towards other disabled people and contrasted this with his previous ignorance saying:

I have demonstrated how little I understood of disability as a junior doctor and how inappropriately negative my attitudes were....I have demonstrated that this was not limited to me. Some of the influences on health care professionals, including society as a whole, medical training that concentrated on disease and individuals, and the bias towards seeing disabled people only when they are sick...³⁸⁵

However, Basnett's paper had a greater influence than just drawing attention to the possible influence of training and the medical culture. It also highlighted the importance of asking doctors themselves the questions this research addresses. This meant not just asking doctors how they make difficult medical decisions for disabled children, but also to reflect on what they think influences those decisions, the factors they consider and the resources they draw upon. Basnett's paper, was a key influence in empirical research with doctors being a major part of this thesis.

Earlier studies as well as the investigation reports cited earlier suggest that certainly for adults, doctors' attitudes can have a huge impact on the treatment and care disabled people receive. As has been seen the position of disabled children has rarely been considered, **something this thesis does, examining**

³⁸⁵ Basnett, I, (2001) 'Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467, p. 462

as it does particularly in chapters five,³⁸⁶ six³⁸⁷ and nine,³⁸⁸ the impact of a doctor's attitude on the treatment a disabled child receives.

To conclude this chapter the key issues that emerge from this scanning of the landscape since 1979 and this thesis' contribution are now summarised.

11. **Conclusions: Key Issues from the literature and this thesis' contribution**

11.1 Key Issues

A scan of the key milestones in law and ethics from 1979 to 2010 relevant to best interest decision-making for disabled children suggests that potentially, very little has changed in how best interest decisions are made for disabled children since the late 1970s when Kennedy first asked 'what is a medical decision?' A question which is a crucial one for the children who are the central focus of this study. It seems it is a question still being asked today and with the answer no clearer. This review also suggests that it is not really known how paediatricians do make decisions for disabled children. It is not a question academia has addressed and it seems to be a question the courts have avoided.

In the almost forty years reviewed in this chapter, 'on paper' there have been huge changes; with the introduction of international human rights treaties directly addressing the rights of children and disabled people; domestic legislation stressing the paramountcy of a child's rights; and professional guidance on making these decisions. However, the review suggests very little has changed in the way the English High Court addresses best interest

³⁸⁶ Chapter five, pp.181-236

³⁸⁷ Chapter six, pp. 237-284

³⁸⁸ Chapter nine, pp. 347-380

decisions for severely disabled children. Indeed, as was seen,³⁸⁹ the High Court has expressly said nothing has changed.³⁹⁰ Society's attitudes towards disabled children have undoubtedly changed. They now live at home with their parents, rather than in institutions and attend school, many even attending mainstream school. It is, however, unclear the extent to which paediatrician's attitudes towards disabled children have changed and whether, doctors approach best interest decisions as narrow medical decisions or as the wide-ranging welfare decisions. It is unclear, whether doctors have the training, education and expertise to make wide-ranging best interest decisions or whether they focus purely on the medical aspects of the decisions and/or make assumptions about the non-medical aspects. Indeed, it seems unclear whether doctors are making decisions in the child's best interests, or being overly influenced in their decisions by their personal and professional characteristics.

Through addressing the research questions in this thesis, it is hoped that a much clearer picture will emerge as to how paediatricians make best interest decisions for disabled children. This thesis cannot and does not try to answer whether doctors make decisions in the best interests of individual disabled children. It does address the extent to which paediatricians are making best interests as they are guided to do by their professional ethical guidance and, the jurisprudence of the English High Court and the part if any, played by law, rights and ethics in those decisions.

11.2 This thesis' contribution

The contribution this thesis makes can be summarised as follows:

- i) It asks UK paediatricians directly how they make difficult decisions (best interest decisions) for severely disabled children, as opposed to

³⁸⁹ Chapter two, para 7, pp. 62-63

³⁹⁰ *Portsmouth NHS Trust v Charlotte Wyatt* [2005] EWHC 117 (Fam)

- infants. It asks doctors to reflect on their own and their medical colleagues' decision-making;
- ii) It identifies the factors the paediatricians use to make their decisions and the weight they put on each of those factors;
 - iii) It inquires as to the impact, of any, of key professional and personal characteristics on the paediatricians' decisions, including the impact if any of personal experience of disability;
 - iv) It asks UK paediatrician about their training and education in law, rights and ethics; it maps this to what the doctors say about how they make their decisions and in doing so tests Kennedy's hypothesis that doctors do not have the training and education needed to make these decisions;
 - v) It tests the UK government's claim that all professionals who work with children receive training in the UNCRC, by asking UK paediatricians directly about their training in child rights;
 - vi) It asks, if and how, UK paediatricians use guidance from their professional bodies when making their decisions for disabled children;
 - vii) It highlights importance of differences between children and infants when making best interest decisions.
 - viii) It builds on the normative debate of *should* doctors make quality of life decisions about disabled patients by asking doctors their views and includes disabled children in the debate. It also asks doctors directly whether doctors they *do* make quality of life decisions about their disabled child patients;
 - ix) It considers the impact of disagreements between doctors as to a child's best interests;

- x) It identifies two distinct 'camps' of paediatricians³⁹¹ who seem to approach best interest decisions qualitatively differently and a potential new schema of legal consciousness³⁹²;
- xi) It asks doctors about the role played by law, rights and ethics, if any, in their difficult decisions for children.

As shall be seen in chapter seven and nine, having analysed that the doctors say about law, rights and ethics using the legal consciousness framework explained in chapter seven, this thesis also propose a new category of legal consciousness. This reflects a legal consciousness identified in some of the doctors in this study, but not found in existing legal consciousness literature.

In the next chapter the methodology used in this thesis is set out and explained.

³⁹¹ Chapter six, paras 7.2.1-7.2.2, pp.268-271

³⁹² See chapter seven, para 11.3, p. 321

Chapter Three

Methodology

1. Introduction

This chapter describes the methodology used for the empirical research, namely the survey of paediatricians and subsequent interviews, in this thesis. The chapter is divided into three parts ('A, B, C). Part A describes the methods employed in preparation to generating the data, including addressing ethical issues. Part B describes how the data was generated and part C describes how it was analysed.

As was mentioned at the very start of this thesis,³⁹³ the existing lenses set out and discussed in chapter two are used to explore how, by their own accounts, UK paediatricians make difficult medical decisions for disabled children. A legal consciousness conceptual framework is then discussed and justified in chapter seven,³⁹⁴ before being used in chapters eight and nine, to fill in the gaps left by these existing lenses and examine how UK paediatricians make sense of and conceptualise law when making these decisions. An on-line survey and semi-structured interviews were used to gather the data analysed through the rest of this thesis.

Semi-structured interviews are commonly used in legal consciousness studies,³⁹⁵ as they allow for in-depth reflection and discussion of the issues, allowing participants to more freely reveal their legal consciousness. Surveys are less commonly used, as the brevity of the answers do not so readily reveal the participants' legal consciousness. However, internet based surveys have

³⁹³ Chapter one, para 1, p.1

³⁹⁴ Chapter seven, pp.285-321

³⁹⁵ See for example, Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74; Cooper, D (1995) Local Government Legal Consciousness in the shadow of Juridification, *Journal of Law and Society*, 22(4), 506-26; Ewick, P, Silbey, SS, (1992), Conformity, Contestation and Resistance: An Account of Legal Consciousness, *New England Law Review*, vol. 26

been used by some legal consciousness scholars, including, for example, Harding,³⁹⁶ who identifies some of their advantages:

‘including the potential for; access to a diverse range of participants, international scope, anonymity and confidentiality, and the potential for large number of respondents.’³⁹⁷

Not all these reasons apply to this thesis, for example this thesis is only concerned with UK paediatricians, but using an online survey did allow for a much large number of participants than would have otherwise been possible within the time and financial constraints of this study. It also allowed for participants who wanted to remain anonymous to take part, or for participants who only wanted to answer some questions to easily do so. Moreover, several of the survey questions, in addition to asking participants to choose from a range of answers, allowed for free-flowing text to be added by the participants, giving greater insights into their thinking. More details of the reasons for adopting a legal consciousness approach to analyse what the doctors said about law are given in chapter seven.³⁹⁸ This chapter focuses on the methods used to collect and analyse the data.

Part A: Preparing for Data Generation

2. Ethical Considerations

This study raised several ethical considerations. These were given considerable thought and discussed at some length with the PhD Supervisors. The issues raised as a result of the researcher’s personal status were touched

³⁹⁶ Harding, R, (2006) ‘Dogs are ‘registered’, People shouldn’t be’ *Legal Consciousness and Lesbian and Gay Rights, Social and Legal Studies*, 15 (4),511-533

³⁹⁷ *Ibid*, p. 519

³⁹⁸ Chapter seven, pp.285-321

on in chapter one.³⁹⁹ The steps taken to address these and wider ethical issues are now presented.

2.1 Ethical Clearance

The University of Edinburgh's College of Humanities and Social Sciences research ethics framework guided all ethical considerations and actions in this study. The study gained ethical approval from the Law School. Standard research ethics forms were completed setting out the nature of the research, identifying the potential ethical risks and the steps to be taken to minimise these risks for all parties, including the researcher. As research was to be conducted with NHS employees and potentially on NHS premises, ethical clearance to conduct the survey and subsequent interviews was sought from the NHS South East Scotland Research Ethics Committee. The NHS South East Scotland Research Ethics Service deemed this thesis to be a best practice audit aimed at improving patient care rather than research requiring ethical clearance, stating 'it does not need NHS ethical review under the terms of the Governance Arrangements for Research Ethics Committees in the UK'.⁴⁰⁰

The NHS Health Authority Guidance⁴⁰¹ also states that research ethics committee guidance is not needed where 'Research limited to the involvement of NHS or social care staff recruited as research participants by virtue of their professional role.'⁴⁰² This research also falls within this exception.

³⁹⁹ Chapter one, paras. 5.2-5.3, pp.12-21

⁴⁰⁰ Letter dated 13th April 2010 from South East Scotland Research Ethics Service to the researcher. See copy at Appendix 3

⁴⁰¹ NHS Health Research Authority, (2011), *Governance Arrangements for Research Ethics Committees*, NHS HRA, London, <http://www.hra.nhs.uk/resources/research-legislation-and-governance/governance-arrangements-for-research-ethics-committees/> last accessed 24 May, 2017

⁴⁰² Ibid

2.2 Participants' Status

The first ethical problem raised by this research is its subject matter. This study raises questions about the care of a very vulnerable population of patients. The patients are vulnerable because they are children; they are sick, indeed often seriously ill, even dying and have significant physical - and often also significant cognitive impairment. Due to the extreme vulnerability of the patients, a decision was made early in the research process not to involve the patients or their families directly in the research. While merit was seen in including the perspective of child patients when possible⁴⁰³ and the perspective of their families, it was recognised that considerable hurdles would have to be overcome to speak directly with patients and their families and these hurdles were seen as being too great, in view of the time and resources available, for this thesis. Instead it was decided to focus this study on the perspective of doctors as the providers of care, studying their legal consciousness. The perspective for doctors, as seen in the last chapter,⁴⁰⁴ has been explored by researchers for infants and disabled adults, but not children.

Doctors are clearly not a vulnerable group, rather they are an elite one. However, it is perhaps important to explain why this assertion is made and what is meant in this thesis by 'elite'. 'There is no clear-cut definition of 'elite' and social science scholars to use the term in different ways.'⁴⁰⁵ The doctors in this survey are, professional elites, a status obtained by being 'highly skilled, professionally competent' and also 'class specific.'⁴⁰⁶

⁴⁰³ Many of the children will have significant cognitive and communication impairments, although there will be a small number of children within the cohort who would be able to communicate their views.

⁴⁰⁴ Chapter one, para.2, p.3

⁴⁰⁵ Harvey, WS (2011) Strategies for conducting elite interviews, *Qualitative Research*, 11(4), 431-441 at p.432

⁴⁰⁶ McDowell, L (1998) Elites in the City of London: some methodological *considerations*, *Environment and Planning*, 30(12), 2133-2146, at p.2135

The term 'elite' is used by Stephen⁴⁰⁷ to indicate the relationship between individuals or groups. Doctors, especially senior consultants⁴⁰⁸ are elites in several senses: elites when compared with the population as a whole;⁴⁰⁹ elites when compared with other health professionals; and most importantly for this study, elite in relation to the children at the centre of these decisions and their families. Doctors' elite status can therefore be seen to arise for several often interrelated reasons, including their socio-economic status in society, their relationships and their professional expertise. The potential of this professional expertise to lead to deference from the courts towards doctors was seen in the last chapter,⁴¹⁰ arguably making doctors a particularly powerful elite. The impact or otherwise of doctors' elite status on their legal consciousness is considered later in this thesis in chapters three and nine.⁴¹¹

Harvey recognises that within elites there can be a hierarchy, with 'ultra-elites' being those in the most influential positions within an elite group.⁴¹² If doctors as a class are an elite, senior consultants, especially those who hold influential positions, for example, heads of departments, clinical directors or posts with medical royal colleagues influencing policy and practice nationwide, can be said to be 'ultra-elites'. Indeed, as shall be seen in chapter six, there is a suggestion from doctors in this study, that there is a hierarchy between the paediatric sub-

⁴⁰⁷ Stephens, N (2007) Collecting data from elites and ultra-elites: telephone and face-to-face interviews with macroeconomists, *Qualitative Research*, 7(2), 203-216, at p.205

⁴⁰⁸ As shall be seen in chapter four, para 4.7, p.161. 97% of the doctors in this study held consultant posts.

⁴⁰⁹ Ibid

⁴¹⁰ Chapter two, para 3, pp. 34-43

⁴¹¹ Chapter three, para2.2, pp.98-102, Chapter nine, para, 3.1, p.363

⁴¹² Harvey, WS (2011) Strategies for conducting elite interviews, *Qualitative Research*, 11(4), 431-44, at p.432

specialities, with PICU consultants at the top of this hierarchy.⁴¹³ However, as Harvey recognises:

‘In many cases, it is not necessarily the figureheads or leaders of organisations and institutions who have the greatest claim to their elite status, but those who hold important social networks, social capital and strategic positions within social structures because they are able to exert influence.’⁴¹⁴

Harvey’s quotation resonates with the concept of the ‘hidden curriculum’ suggesting that all doctors can potentially be said to have elite status in relation to newcomers to their profession. The impact of the ‘hidden curriculum’ was described by Hafferty and Franks:⁴¹⁵

Most of what the initiates (medical students) will internalize in terms of the values, attitudes, beliefs and related behaviours deemed important within medicine takes place not within the formal curriculum but via a more latent one, a ‘hidden curriculum’ with the later being more concerned with replicating the culture of medicine than with the teaching of knowledge and techniques’.⁴¹⁶

In other words, medical students are socialised from being merely lay people into medics, often learning more from role models rather than from their formal teaching. However, Hafferty and Franks voiced a concern that that this process is ‘largely unobserved unmonitored and highly idiosyncratic’.⁴¹⁷ Students may be taught one thing formally, while on the wards learn from more senior doctors that very different behaviour is accepted or even expected, leading to ‘inconsistencies, contradictions and ‘double messages.’⁴¹⁸ For example, a medical student may learn about disability discrimination in the classroom, but

⁴¹³ Chapter six, para 5.2, .1.1, p.254

⁴¹⁴ Harvey, WS (2011) Strategies for conducting elite interviews, *Qualitative Research*, 11(4), 431-441 at p. 433

⁴¹⁵ Hafferty, F, Franks R, (1994) The Hidden Curriculum, Ethic Teaching and the Structure of Medical Education, *Academic Medicine*, Vol. 69(11), pp.861-871

⁴¹⁶ *Ibid*, pp. 864-5

⁴¹⁷ *Ibid*, p. 863

⁴¹⁸ *Ibid*, p.866

then hear senior staff referring to cognitively impaired patients as ‘a bunch of nutters.’⁴¹⁹ The ‘hidden curriculum’ can also manifest itself in, for example, ethical issues being given very little time or prominence in the curriculum,⁴²⁰ suggesting to students’ that ethics are less important than clinical topics. Doctors’ room chats can also reinforce a particular attitude towards patients or indoctrinate negative attitudes.⁴²¹ The impact, if any, of the hidden curriculum on doctors’ best interest decisions will be considered through this thesis.

Although clearly elites and in that sense not a vulnerable population,⁴²² it was recognised that this study would be asking doctors very probing questions about very sensitive issues. Doctors would, be asked how they decide whether an individual child lives or dies. Doctors were also being asked about their knowledge of and adherence to the law, both criminal and civil. This is an area not without controversy and increasingly during the time this study, the political and media spotlight has focused more and more on the behaviour of health professionals in relation to vulnerable patients, as was seen in the last chapter.⁴²³

It was recognised that doctors were being asked to reflect on their and their colleague’s clinical decisions and analyse these. They were also being asked

⁴¹⁹ Francis, R, (2010) *Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005 – March 2009*, Vol 1, The Stationery Office, London, para 212

⁴²⁰ By way of example first year medical students at Edinburgh University study two courses, one dealing with clinical aspects of health and the other with ethical aspects. However, the clinical course is titled “The fundamentals of medicine”; whereas the ethics course is titled “health ethics and society”, suggesting that clinical aspects are more fundamental to the role of a doctor than ethics.

⁴²¹ Francis, R, (2010) *Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005 – March 2009*, Vol 1, The Stationery Office, London, para 212

⁴²² Although see chapters six, pp.237-284 and nine, pp. 347-380 post, where doctors in this study suggest they see themselves as vulnerable.

⁴²³ Chapter two, para 8. P. 75-79. See also The Mid-Staffordshire NHS Foundation Trust Public Inquiry (2013) *Report of the Mid-Staffordshire NHS Foundation Trust Public Inquiry*, volume 3, HC898-111, The Stationery Office, London and Kirkup B, (2015), *The Report of the Morecombe Bay Investigation*, The Stationery Office, London

to reflect on the care they had given to children who had died and to question the judgments they had made. Considerable thought therefore went into the planning of questions for both the survey and interviews. It was seen as important to ensure that data could be obtained, while minimising any distress and discomfort to the doctors, while still encouraging them to think deeply about and discuss these issues. To address this, the participants could choose not to answer any single or group of questions in the survey. As will be discussed, questions were limited where doctors who advised on the survey content, suggested those issues may be particularly sensitive ones for doctors. Doctors who were interviewed could choose the location of their interview to ensure they were in a location where they felt comfortable. The doctors were also told at the start of the interview that they could choose not to answer any question or stop the interview or withdraw from the study at any time.

2.3 Researcher's Personal Status

The researcher was also in an unusually potentially vulnerable situation as a parent (and in the later years of the study, newly bereaved parent) of a child who fell within the profile of the children under discussion. Much thought was given in preparing, particularly for the interviews, as to the sort of information the doctors may impart, unaware of the researcher's personal situation. Consideration was, for example, given as to how the researcher would deal with any distressing information encountered in the survey responses and more particularly in the interviews. The researcher's many years of engaging with doctors as a parent was seen as an asset, since, as mentioned in chapter one,⁴²⁴ the researcher was familiar with the types of comments some doctors could unwittingly make about disabled children. As discussed in chapter one,⁴²⁵ the researcher also had significant experience of working with doctors on research; guidance and national investigation committees involving this same

⁴²⁴ Chapter one, paras. 5.2, pp. 12-20

⁴²⁵ Chapter one, para 5.3, p.20-21

demographic of children, so was not unaccustomed to hearing, for example, the deaths of children being discussed in a dispassionate manner. Finally, as was also mentioned in chapter one,⁴²⁶ the researcher's experience as a practising lawyer was also viewed as helpful in maintaining a professional distance.

The researcher and her supervisors discussed at length the issue of the whether doctors should be made aware of the researcher's personal circumstance. The decision was made that this should not be revealed, unless a doctor expressly asked (in which case it was felt important to be honest with doctors). This decision was based on the importance of the doctors responding to the survey and interview questions, without being influenced in their answers by the researcher's personal status.

It will be recalled from chapter one⁴²⁷ that this study excluded doctors working at the hospital where the researcher's son had most of his care at the time of the survey and interviews. The hospital is a small one. Even doctors from that hospital who had not worked with the researcher's son were excluded, as it was likely they would know of him and there was a real possibility that they may work with him in the future. It also excluded doctors at other hospitals who had worked with the researcher's son, but not doctors generally, due to the low likelihood of those doctors knowing the researcher as a parent or working with the researcher's son in the future. One doctor who responded to the survey did subsequently become directly involved in the researcher's son's care. He was therefore not approached for interview, although his survey responses were kept within the results. The researcher intended seeking that doctor's consent to keep him in the study, but the doctor was removed from the GMC register, for unrelated reasons, before the request could be made.

⁴²⁶ Ibid

⁴²⁷ Chapter one, para 5.2, p.17

A decision was made not to exclude all hospitals completely where the researcher's son had received care, as they were much larger and the researcher's son had received only short-term care from a small number of staff. Excluding all doctors from all these hospitals was thought to be unnecessary. It would have excluded too many potential participants from the research and excluded doctors from most of the UK's children's hospitals with no knowledge of the researcher or her son.

As was mentioned in chapter one, the researcher's son died while this thesis was being researched and written. All the empirical data had been generated prior to his death. The particular circumstance of Adam's death made reading and analysing much of the data exceptionally traumatic. The researcher dealt with this by taking time away from this thesis when needed and seeking professional bereavement support.

2.4 Protecting the identities of the participants

To protect the identity of the doctors in this study, doctors' names and place of work have not been revealed and the doctors were assured of this. In the data analysis, each doctor is given a number. Doctors were told that where relevant their health region and specialism would be identified, but not in conjunction with information that would make a doctor easily identifiable to colleagues. Both the researcher and the doctors recognised that complete anonymity could not be guaranteed as, particularly within specialisms, doctors tend to know each other and may be able to identify a colleague from a quoted phrase or limited personal details. By way of (fictional) example, a consultant neurologist working in Scotland who trained in a particular region or who worked abroad may be identifiable by colleagues from this limited information. The sample group proved to be relaxed about this. All had personal experience of academic research and other than one doctor who expressly asked that a particular phrase not be quoted directly, expressed their lack of concern on this issue. Data is presented in such a way to avoid a doctor being identified. Particular care was taken not to identify particular doctors when talking about their status

as parents of disabled children. This was recognised as being a characteristic, which could make a doctor particularly easy to identify, by colleagues. For this reason, this characteristic is analysed in less depth than might have been interesting for this study.

Throughout the whole of this thesis all data identifying doctors has been stored on a computer only accessed, and only accessible by, the researcher. All data is password protected.

3. Creating the Survey

The Bristol Survey on-line survey tool created by the University of Bristol⁴²⁸ was used to develop the survey,⁴²⁹ a copy of which can be found in appendix two. The questions included in the on-line survey were developed from the thesis research questions listed in chapters one.⁴³⁰

The survey included attitude questions, to assess how the respondents felt about something; behaviour questions, questions about the doctors' beliefs about their own behaviour and attribute questions to elicit information about the doctors' ages, education and training, as well as information about their religious upbringing and their familiarity and involvement with disabled people outside of work.

The survey, was developed with six sections. Section one asked the doctor for basic personal and demographic background information, for example, name; contact details, specialism and whether the doctor would be willing to discuss the issues raised in the survey further with the researcher. Section two asked

⁴²⁸ <http://www.survey.bris.ac.uk>

⁴²⁹ See Appendix 4, pp. 427-433

⁴³⁰ Chapter one, para 3, p.7

the doctors about their medical education; training and current post. The purpose of these questions was to try to ascertain whether where doctors train and work influences their medical decision-making for disabled children with complex health problems. Section three was entitled 'Child Dependent Factors'. This asked doctors about making difficult decisions for disabled children.

Doctors were deliberately not asked directly about 'best interest' decisions or 'end of life' decisions but rather asked:

'What sort of difficult decisions do you find yourself making when dealing with disabled children?'⁴³¹

This was because it was felt important for the doctors to frame what they saw to be difficult decisions and to see whether they explicitly or implicitly referenced a child's best interests when not prompted to do so. Doctors, however, were expressly asked about severely disabled children with complex health problems,⁴³² rather than children generally. This is because disabled children are the focus of this thesis and not making this clear may have meant respondents did not mention disabled children at all. This in itself would have been an interesting finding, but would have given very little data to analyse in respect of doctors' decision-making or legal consciousness in relation to disabled children.

The doctors were also asked questions about how they make decisions, both what factors they consider and whom they consult with or involve. Questions were also included about the doctors' level of confidence when making decisions and whether they encounter disagreement and if so how they deal with it.

⁴³¹ Appendix 4, question 19, p. 429

⁴³² Appendix 4, p.427

Section four asked doctors about law, rights, ethics and their use of professional guidance. There is a view among some legal consciousness scholars that law should not expressly be raised with research participants as whether a participant mentions law in itself reveals something about his or her legal consciousness.⁴³³ Other scholars do raise it, indeed, the context of the research can make it inevitable, see for example Ewick and Silbey.⁴³⁴ In this study, because it was felt important to capture how doctors perceived their decisions in relation to the law, rights and professional ethics, reference was made to the law in the survey, but only after the doctors had answered detailed questions on how they make difficult decisions. It was also felt important to test Kennedy's ⁴³⁵ assertion and that made in *Glass v UK* (2004)⁴³⁶ discussed in the last chapter,⁴³⁷ that doctors have no training to make legal and ethical decisions. Doctors were, therefore, asked about any training and/or education they had undertaken in law, rights and ethics, either pre-or post-qualification. They were also asked questions to ascertain how relevant they thought law, rights and ethics to be to their decision-making and how, if at all, they used, law, rights, ethics and professional guidance when making decisions.

Section five of the survey asked the doctors about resources and the impact of resources, if any, on their decision-making, to ascertain whether they saw resources as relevant to their decisions for disabled children. The final section of the survey asked doctors more questions about their backgrounds. For example, doctors were asked about whether they have lived or worked abroad;

⁴³³ Harding, R, (2006) 'Dogs are 'registered', People shouldn't be' *Legal Consciousness and Lesbian and Gay Rights, Social and Legal Studies*, 15 (4),511-533 at p.515

⁴³⁴ Ewick, P, Silbey, SS, (1992) *Conformity, Contestation and Resistance: An Account of Legal Consciousness, New Eng. L. Rev*, Vol. 26

⁴³⁵ Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form in Kennedy, I, 2001, *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31.

⁴³⁶ *Glass v United Kingdom* [2004] 61627/00_ECHR 103 (9 March 2004)

⁴³⁷ Chapter one, para 5.1, p. 11

about whether they had children; about their personal experience of disability and about any religious upbringing or faith. The aim of these questions was to ascertain as far as possible, whether any of these personal factors influence doctors' decision-making. It was recognised that with a survey of this size it would be difficult, if not impossible, to show a causal link between a particular attribute of a particular doctor and a particular way of deciding for disabled children. Indeed, it seemed possible, if not inevitable that each doctor is influenced by a multitude of factors when making a single decision. However, it was hoped that by asking these questions, any potential tendencies for doctors with particular attributes to decide in a particular way could be highlighted for further research.

4. Piloting and modifying the survey

To ascertain the content validity of the survey, once drafted it was discussed in detail with three consultant paediatricians and two PICU nurses. Two of the consultants were very senior and one was newly in post. All the doctors and nurses worked closely with disabled children with complex health problems and were chosen because of their high level of expertise in the field. The senior consultants were involved strategically at national level in the planning of care for disabled children with complex health needs. Kelley et al recommend involving:

‘experts in the field, colleagues and members of the target population in question design in order to ensure the validity of the coverage of questions included.’⁴³⁸

The discussions involved one face-to-face meeting with one of the senior consultants, and a second face-to-face meeting jointly with the other senior consultant and the newly qualified consultant. The two nurses were interviewed individually. The consultants and nurses all answered the survey and the

⁴³⁸ Kelley, Clark, B, Brown, V, & Sitzia, J (2003) Good practice in the conduct and reporting of survey research, *International Journal for Quality in Health Care*, 15(3), 261-266. p. 263

anticipated interview questions, as if they were participants. In addition, they discussed the questions, both their content and form. The meetings proved to be extremely constructive and highlighted questions where there was the potential for a doctor to understand the question differently from the researcher as a lawyer.

Concern had been raised in earlier discussions with supervisors that doctors may be wary of taking part or addressing the questions raised in this thesis. Whilst this may have been a factor for some doctors and a reason not participating, the positive responses of the three consultants involved in these early discussions was noteworthy. All three commented upon how important they thought the questions the survey was addressing to be and how pleased they were that the research was being done. These sentiments were, as was seen in chapter one,⁴³⁹ later echoed by a number of the research participants.

5. Planning the interviews

The purpose of the interviews in this study was to hear from doctors how the doctors themselves understand their own difficult medical decisions for disabled children with complex health problems.

Semi-structured interviews were chosen due to their 'flexible and fluid nature',⁴⁴⁰ which is 'intended to generate interviewees' accounts of their own perspectives, experiences, understandings, interpretations and interactions'⁴⁴¹ and 'allow unexpected themes to emerge'.⁴⁴² Indeed, as shall be seen in chapter six,⁴⁴³

⁴³⁹ Chapter one, para 5.2, p.16

⁴⁴⁰ Mason, J, (2011)' Semi-structured Interview', in Lewis-Bench, MS, Bryman, A, Futing, L, (eds), *The SAGE Encyclopaedia of Social Science Research Methods*, SAGE, Thousand Oaks, p.1021

⁴⁴¹ Ibid

⁴⁴² Ibid

⁴⁴³ Chapter six, paras 7, pp. 261-275

disagreements between doctors emerged as a strong theme in this thesis. This had not been expected. The semi-structured nature of the interviews enabled the researcher to address with the participants the research questions, but also allowed the researcher the freedom to explore them slightly differently with each doctor, depending on the individual doctor's responses, experiences and views. It also enabled the doctors to talk about the issues they felt most relevant and important to them. Indeed, the extent to which individual doctors chose in his or her interview to talk about law can, to an extent, be seen as an indication of how relevant that doctor saw law to his or her best interest decision-making.

Prior to planning the interview questions, a preliminary analysis of the doctors' survey responses was undertaken and key emerging themes identified. These were disagreements between doctors; the impact of a child's cognitive ability; uncertainty and relevance to law to difficult medical decisions for disabled children. Interview plans were then drafted addressing these themes in the context of the study's research questions. A sample interview plan is included at appendix four.

Questions were also prepared to encourage doctors to expand on the answers they had given in their survey responses. The aim of the questions was to encourage doctors to reflect on their clinical decision-making. As with the survey a 'difficult decision' was intentionally not defined but left for the doctors to define in an attempt to ascertain what types of decisions doctors themselves perceive to be difficult. Questions were also drafted inquiring about doctors' training in law, rights and ethics and how, if at all, doctors used these in their decision-making.

Care was taken to word all questions so that they were open, with the aim of encouraging doctors to reflect, consider and discuss at length their view and opinions, so revealing their decision-making and their legal consciousness. Care was also taken in the language used, not to give the impression that a particular answer was expected, or that there was a right or a wrong answer.

Questions were prepared asking doctors how they made difficult medical decisions for disabled children with complex health problems; whom they involved in the decision-making, and how easy or difficult they found each aspect of these decisions to make.

Particular questions were also drafted for particular doctors based on their survey responses. For example, specific questions for doctors who had trained or lived abroad asking about the impact, if any, of this experience on their decision-making, or questions for doctors who highlighted the importance of their faith on their decisions. Specific questions were also put to doctors who were parents. Questions were drafted as mere prompts to encourage doctors to reflect and speak freely and at greater length about a particular issue that they had mentioned in their survey.

A quotation from Aaron and Schwartz,⁴⁴⁴ which was cited in a 1994 House of Commons research paper on rationing health,⁴⁴⁵ was also prepared to use as a prompt to encourage doctors to reflect on their role, if any, in the allocation of resources to disabled children with complex health problems:

‘British physicians often appear to rationalize or at least redefine, medical standards so that he can deal more comfortably with resource constraints...Thus it is clear that not all British doctors believe they are providing all potential beneficial care to their patients. Many realize, according to one consultant, that they are acting as society’s agent in rationing care’.⁴⁴⁶

A quotation was chosen to prompt discussion as it thought unlikely that doctors would acknowledge that treatment for disabled children is rationed if asked directly. A 1984 quotation, rather than a contemporary one was deliberately

⁴⁴⁴ Aaron, HJ, Schwartz, WB, (1984) *The Painful Prescription, Rationing Hospital Care*, Brookings Institution Press, Washing DC

⁴⁴⁵ House of Commons (1993) *Prioritising Health – The Debate about Health Care Rationing*, Research Paper, 93/49, Houses of Parliament, London

⁴⁴⁶ Ibid, p.10

chosen, as it seemed less threatening to doctors, by not suggesting in any way that it described their current practice. However, it is acknowledged that it also potentially facilitated the doctors challenging the quote too easily as being out of date. The doctors were asked if the quotation chimed with their experiences, in the hope that this would lead on to further discussion on the impact of resource allocation on disabled children with complex medical problems.⁴⁴⁷

PART B– Generating the data

6. The Population

The population of interest for this thesis and therefore the potential participants for this research, were UK-based paediatricians. The survey was conducted between April and September 2010. The RCPCH, the professional body for paediatricians in the United Kingdom, conducts periodic studies of the demographics of UK paediatricians. The RCPCH did not conduct a workforce survey in 2010, however, its workforce survey for 2009, published two years later in 2011, reports that there were then 4,789 paediatricians employed in the UK.⁴⁴⁸ This figure fell to 4,605 by the time of the next workforce survey in 2011.⁴⁴⁹

⁴⁴⁷ For reasons of space, due to the majority of doctors not seeing resources as an issue in decision-making for disabled children, this question is not returned to in any depth in later chapters. Dr 24 did however, say in her interview that she thought resources did play a part with a parent and doctor's ability to lobby hospital managers on behalf of a particular child playing an important part in the support a child received, especially in the community. Dr 32, as is discussed in chapter ten, voiced strong criticisms of what he saw as intensive care consultants seeing themselves as gate keeper of resources and so making resource based decisions as to whether a disabled child should have access to intensive care.

⁴⁴⁸ RCPCH, (2011), *RCPCH Medical Workforce Census 2009*, Royal College of Paediatrics and Child Health, London, http://www.rcpch.ac.uk/system/files/protected/page/RCPCH%20Workforce%20Census%202009%20for%20web2_1.pdf accessed 1 November 2015

⁴⁴⁹ RCPCH, (2013), *RCPCH Medical Workforce Census 2011*, Royal College of Paediatrics and Child Health, http://www.rcpch.ac.uk/system/files/protected/page/RCPCH%20census%20FINAL_0.pdf accessed 1 November 2015

A sample pool of 368 paediatricians was selected using the methods outlined below, but in simple terms, being the paediatricians, whose contact details could be sourced from the public domain within the restraints of this study, with particular effort being made to recruit consultants working in the paediatric subspecialties thought most relevant to this thesis. In addition to the 368 paediatricians approached directly, professional bodies for key paediatric subspecialisms were also approached and asked to pass a link to the survey to their members, as described later in this chapter.

Paediatricians were selected with the aim of harnessing the insights of as many paediatricians as possible, who regularly make difficult medical decisions for disabled children with complex health problems. It was recognised right from the start of this study that since the participants once invited, were self-selecting, the doctors in this study might not to be representative of paediatricians generally. The aim of the survey was therefore to generate a sample, but not necessarily a representative sample, of the views of highly experienced paediatricians, particularly those who are making decisions whether to withhold or withdraw care from disabled children with complex health needs in the day-to-day course of their work.

PICU consultants, paediatric neurologist and paediatric respiratory consultants were particularly targeted when they could be identified as such, being the subspecialties of paediatricians most commonly involved in best interest decisions for disabled children with complex health problems. The sampling was therefore purposive, as it was based on the judgment of the researcher⁴⁵⁰ as to which paediatricians would be most likely to be involved in these sorts of decisions. However, the survey was also sent to paediatricians beyond these sub-groups, both to allow for the researcher's judgment to be challenged and also, if the data showed the researcher's judgment to be correct, to enable a

⁴⁵⁰ See Chapter one, paras 5.2-5.3, pp.12-21, for a discussion of the researcher's background

comparison to be made between different sub-specialties. The issue of non-participation by doctors in this study and its significance or otherwise is discussed later in this chapter.

Thirty-nine requests to participate were sent to doctors who could be identified as PICU consultants; fifty-five to paediatric consultants identified as respiratory specialists and sixty-three to paediatric consultants identified as being neurology consultants. A further seventy-five requests were sent to paediatric consultants whose specialisms could be identified, but were not neurologists, respiratory or PICU consultants. This sub-group included, for example, paediatric endocrine, oncology and nephrology consultants. A further 136 requests to take part in the study were sent to consultants who could be identified as paediatricians, without a sub-specialty within paediatrics being identifiable. It is possible that this group included some who were PICU, respiratory or neurology consultants. Finally, six requests were sent to community paediatric consultants. Although community consultants will not usually be the primary doctor making the type of decision which is the subject of this study, they can commonly be the lead consultant for a disabled child and so play a very influential role in the lives, including being involved with acute doctors in decisions. The insights of community paediatricians were therefore felt to be relevant to this study not just for what they could say about their involvement in the decisions, but also for their perceptions as to how their acute colleagues make such decisions. Community consultants will often have knowledge of or be involved in decisions about a child's life outside of the hospital, for example, their schooling or access to therapies or support services. They also often have very long-term relationships with children and their families, sometimes lasting the whole of a child's life.

7. Paediatric Sub-Specialties

As at November 2009⁴⁵¹ there were 128 PICU consultants, 110 paediatric neurologist/neuro-disability consultants, and eighty-one respiratory consultants in post within the UK.⁴⁵² This study therefore approached 30% of PICU consultants; 57% of the UK's paediatric neurology consultants and 68% of the UK paediatric respiratory consultants. The percentage of PICU consultants is lower than for the other two specialisms as PICU consultants proved more difficult to access, their email contact details not usually being in the public domain. As shall be discussed later, a higher percentage of respiratory consultants were contacted over a period of time, because of the initially low response rate from consultants practicing this sub-specialism.

Figure 1: Survey requests issued and potential population

	Population	Requests sent to	% of population sent a survey
UK Paediatricians 2009	4,789	368	8%
PICU consultants	128	39	30%
Respiratory consultants	81	55	68%
Neurologists	110	63	57%
Other sub-specialists where sub-specialism known	unknown	75	
Other sub-specialists where sub-specialism unknown	unknown	136	

⁴⁵¹ The date of the closest RCPCH workforce survey to the time when doctors completed the survey

⁴⁵² RCPCH, (2011), *RCPCH Medical Workforce Census 2009*, Royal College of Paediatrics and Child Health, London, http://www.rcpch.ac.uk/system/files/protected/page/RCPCH%20Workforce%20Census%202009%20for%20web2_1.pdf accessed 15 November 2015

8. Demographics and diversity in the sample

Consultants as opposed to junior doctors⁴⁵³ were primarily approached for two reasons. First, the care of disabled children with complex health needs is usually consultant led and secondly, for the practical reason that, unlike consultants, the email addresses of junior doctors are not normally in the public domain. Consultants were, however, asked to pass the link to the survey to junior doctors, as well as to complete the survey themselves. The views of junior doctors were thought to be relevant, not least to ascertain whether, and if so how, they were involved in these decisions. The perceptions of junior doctors as to how they believed consultants made decisions was also of interest. Since this study was also interested to learn from doctors the impact on their legal consciousness of any training in law, the views of junior doctors were sought to try capture the impact of any changes in the curriculum in this regard in recent years. The consultants would have qualified at least ten years prior to the survey and most, many years earlier, whereas the junior doctors would have qualified much more recently

An effort was made to include female doctors in the sample group. This study explores different sorts of influences upon doctors' difficult decision-making and so it was thought important to include female doctors where possible. As at November 2009, 46.6% of the paediatric consultant workforce were women, although this drops to 40.4% in tertiary care, where most the target sample group were based.⁴⁵⁴ The RCPCH survey does not report the percentage of women working in individual sub-specialties, so it is not possible, within the cost and time restraints of this thesis, to ascertain the number of women working as

⁴⁵³ A qualified doctor who has not completed his or her training and obtained consultant status.

⁴⁵⁴ RCPCH, (2011), *RCPCH Medical Workforce Census 2009*, Royal College of Paediatrics and Child Health, London
http://www.rcpch.ac.uk/system/files/protected/page/RCPCH%20Workforce%20Census%202009%20for%20web2_1.pdf accessed 1 November 2015

consultants in the core target specialties of PICU, neurology and respiratory medicine. The female doctors in this study are not said to be representative of female doctors. All but one⁴⁵⁵ of the female respondents held senior clinical positions.

The RCPCH survey does not report data with regard the number of doctors employed from black and ethnic minority ('BME') backgrounds, but a conscious effort was also made to include BME into the sample group, by ensuring the inclusion of BME doctors in those sent an invitation to take part in the survey. The identification of BME doctors was by necessity crude, in that the doctors' names were the only information available. Obviously, this is not the best way to ensure a diverse sample. More widely beyond paediatrics as a specialism, the GMC record just 39.5% of UK registered doctors being ethnically 'white British' as at December 2015.⁴⁵⁶ Although 16.1% of UK registered doctors describe themselves as of Indian or Pakistani ethnic origin in the GMC's statistics,⁴⁵⁷ it is acknowledged that a doctor could have a name which appears to suggest he or she is from an black or ethnic minority group, but not be so and likewise, a doctor may be from a black or ethnic minority ethnic group, but this may not be apparent from his or her name. However, in the financial and time confines of this study, including doctors on the assumption that they are of black or ethnic minority origin based on their names was felt to be the best option. The survey then included a question asking doctors to confirm their ethnic origin. As with women doctors, the views of doctors from black and ethnic minority groups were sought in an attempt to have a more diverse sample, and to explore, as far as possible, whether a doctor's cultural upbringing and background, including any religious upbringing, influences how they make difficult medical decisions for children with complex needs and disability.

⁴⁵⁵ One female respondent was a senior registrar, a junior doctor towards the end of her training.

⁴⁵⁶ GMC (2015) *List of Registered Medical Practitioners – statistics*, GMC, London

⁴⁵⁷ Ibid

9. Geographical spread

This study is UK-wide so doctors were sampled from each of Scotland, Wales and Northern Ireland and the nine NHS English Regions existing at the time of the survey, namely Eastern, London, North & Yorkshire, North West, South Central, South East, South West, Trent and West Midlands.⁴⁵⁸

Where possible a tertiary hospital, either a specialist children's hospital or tertiary hospital with a paediatric unit was identified. If neither were identified in the region, a district hospital⁴⁵⁹ employing paediatricians was identified.

Paediatric consultants are not distributed equally throughout the UK, as the RCPCH workforce census confirms:

'London has the highest ratio of consultants to child population (40.9 WTE) compared to 37.4 in 2007. The North East again is the net highest with 33.9 WTE (31.2 in 2007) per 1000,000 0-15 year olds. In contrast the South-East Coast SHA has a ratio of less than 20 consultants per 100,000 children, 19.4 compared with 17.4 in 2007'.⁴⁶⁰

Although not precise, in broad terms, the sample of doctors approached to take part in this survey reflected this regional variation, largely because, self-evidently, there were more potential doctors to approach in the regions with more doctors.

⁴⁵⁸ NHS Medical Directorate, (2009), *A Junior Doctor's Guide to the NHS*, Department of Health, London, p. 9

⁴⁵⁹ Although there is no official definition of teaching hospital or district hospital, doctors often distinguish between the two. A teaching hospital is generally understood as a centre of secondary or tertiary care in a major city that is affiliated with a medical school, often with a large academic department and a reputation for excellence in research. A district hospital (often also called a district general hospital), although a major provider of secondary care in the local area, traditionally lacked a research focus. However, in recent years the distinction has become blurred, as many district hospitals have now become part of medical schools and are actively involved in research. Source: Khan M, (2012) 'Teaching hospital versus district hospital', *BMJ* <http://careers.bmj.com/careers/advice/view-article.html?id=20006282> accessed 20 January 2018

⁴⁶⁰ RCPCH, (2011), *RCPCH Medical Workforce Census 2009*, Royal College of Paediatrics and Child Health, London, at p. 29 http://www.rcpch.ac.uk/system/files/protected/page/RCPCH%20Workforce%20Census%202009%20for%20web2_1.pdf accessed 1 November 2015

10. Identifying potential participants – Survey

Initial contact was made with the consultants in the sample group by email.⁴⁶¹ In England, obtaining the contact details for consultants was relatively straight forward, as most English NHS trusts provided this information on their websites. In the devolved nations of Scotland, Wales and Northern Ireland, NHS Trusts and Boards did not, at the time the sample group was being identified and indeed, mostly still do not, include on their websites, the names and contact details of consultants employed.

To obtain contact details of consultants when this information could not be obtained from trust or board websites, the website <http://www.drfoosterhealth.co.uk/>, which collects and publishes statistical information about healthcare in the UK, was used. The postcode of the relevant hospital was entered in the 'find a consultant' section of the website. 'Children' was then selected as the category; 'any children's disorder' was selected as the condition or procedure and 'paediatrics' was selected as the specialty. The website then produces the names and contact details of paediatric consultants working at the relevant hospital. The search was repeated specifically for paediatric neurologists by selecting 'paediatric neurology' as the 'condition or disorder' and for respiratory consultants by selecting 'lung disorders' as the 'condition or disorder', having already selected 'children' as the 'body area or category'. The website does not give an option to search for a PICU specialist. When contact details were available on NHS Trust or Board websites, these would also give details of the consultant's paediatric sub-specialty. When details of the sub-specialty were not available on the Dr Foster's website, these could sometimes be found by googling the doctor. Often details of the doctor's sub-specialty would be in the public domain because, for example, the doctor

⁴⁶¹ See Appendix 3, p.425

had spoken at a conference, been featured in the media, written a paper or served on a committee, where their sub-specialism was mentioned.

The secretaries of the Paediatric Intensive Care Society; the British Paediatric Respiratory Society and British Paediatric Neurology Association were also contacted by email and asked to forward the link to the survey to their members.

A link to the on-line survey was also distributed by email to the UK Disabled Children's Research Network, a network of academics working in the field of child disability, which includes paediatricians. It was also circulated to members, who are predominately doctors and nurses, of NHS Scotland's National Clinical Network for Children with Exceptional Healthcare Needs by that network. In an attempt to get responses from junior doctors, the BMA UK Junior Doctors' Committee were contacted by email and put information about the study and a link to the survey on the BMA Junior Doctors list server. All doctors sent an invitation to take part in the survey were also asked to forward details of the study and the link to colleagues.

The email sent to all participants outlined the nature of the research and included a link to the survey on the Bristol Survey website. It was sent to 368 individuals.⁴⁶² All individual doctors sent an email who did not reply were sent a second follow up email. Due to the very low response rate from respiratory consultants those doctors were also sent a second follow up letter by post.

Doctors completed the survey by accessing the link to the Bristol Survey website, which took the doctors directly to the survey for this thesis. Two doctors chose to complete a hard copy of the survey and to return it by post. Their data was entered onto the Bristol Survey website by the researcher.

⁴⁶² The emails sent to the organisations mentioned above were sent in addition to these 368 individual invitations

11. Survey response rate

Figure 2: Survey response rate

Sub-specialism	Number of doctors approached	Number of doctors completed survey	% of approached doctors who completed survey
PICU	39	10	26%
Neurologists	63	9	14%
Respiratory	55	2	4%
Other	211	12	6%
Total	368		9%

Note: The 'other' figure is made up of 75 doctors whose sub-specialism was known to be a sub-specialism other than PICU, neurology or respiratory and 136 paediatricians whose sub-specialism was not known.

Thirty-three (9%) of the doctors approached responded to the request and completed the survey. Although this response rate is low, it is comparable with some surveys sent by the RCPCH to its members.⁴⁶³ Doctors as a professional group are also reported by researchers⁴⁶⁴ to be notoriously difficult to get to respond to surveys, because of their busy time schedules and difficulty in locating them⁴⁶⁵ as well as being resistant to surveys.⁴⁶⁶ The researcher also received emails from three doctors apologising for not being able to take part, explaining that their employer had a policy that staff could only respond to research requests from the university linked to their trust.⁴⁶⁷

⁴⁶³ For example, a 2014 survey sent by the RCPCH to its members in Northern Ireland had a 10% response rate; <http://www.rcpch.ac.uk/news/rcpch-northern-ireland-office-launches> accessed 11th July 2016

⁴⁶⁴ see for example, Parsons, JA, Warnecke, RB, Czaja, RF, Barnsley, J, Kaluzny, A (1994) Factors associated with response rates in a national survey of primary care physicians, *Evaluation Review*, 18(6), 756-766. p. 756 & Sobal, J, DeForge, BR, Ferentz, K., Muncie Jr, HL, Valente, CM, Levine, DM (1990) Physician responses to multiple questionnaire mailings, *Evaluation Review*, 14(6), 711-722, p. 712

⁴⁶⁵ & Sobal, J, DeForge, BR, Ferentz, K., Muncie Jr, HL, Valente, CM, Levine, DM (1990) Physician responses to multiple questionnaire mailings, *Evaluation Review*, 14(6), 711-722, p. 712

⁴⁶⁶ Parsons, JA, Warnecke, RB, Czaja, RF, Barnsley, J, Kaluzny, A (1994) Factors associated with response rates in a national survey of primary care physicians, *Evaluation Review*, 18(6), 756-766. p. 756

⁴⁶⁷ Requests had not been sent to the hospital linked to the one where the researcher was based, as this was the hospital where she and her son were already known to most of the doctors.

The response rate varied greatly between the three key sub-specialisms, of PICU, neurology and respiratory medicine, with only one respiratory consultant responding, despite fifty-five respiratory consultants being approached (as compared with sixty-three neurologists and thirty-nine PICU consultants). This does raise the question as to why respiratory consultants did not respond. As Bryman identifies:

‘The problem with non-response is that those who agree to participate may differ in various ways from those who do not agree to participate. Some of the differences may be significant to the research question or questions.’⁴⁶⁸

As they have not responded, it is difficult to know exactly why there was such a poor response rate from respiratory consultants. Is it a reflection of how relevant respiratory consultants think the care of disabled children with complex health needs is to their practice? As Barclay et al ⁴⁶⁹ in their assessment of the non-response of GPs to a postal questionnaire reports, a number of studies⁴⁷⁰ have identified a lack of response with a lack of interest in the survey topic. Alternatively, there may be a more prosaic explanation. For example, do respiratory consultants work in a different way, which makes it less likely that they will respond to a survey of this sort? It is of course not wise to speculate as to why there was a noticeably poor response from respiratory consultants, but the fact that the response rate from one specialism as compared to the two others targeted was so poor, does hint that there was some characteristic specific to respiratory consultants which made them less inclined or able to respond than some of their colleagues. The one respiratory consultant who did take part in the research was asked, when interviewed, for his view on why so

⁴⁶⁸ Bryman A, (2015) *Social Research Methods*; Oxford University Press, Oxford, p. 175

⁴⁶⁹ Barclay, S, Todd, C, Finlay, I, Grand, G, Wyatt P, (2002) Not another questionnaire! Maximizing the response rate, predicting non-response and assessing non-response bias in postal questionnaire studies of GPs, *Family Practice* 19(1), 105-111 doi, 10.1093/fampra/19.1.105

⁴⁷⁰ E.g. Armstrong D, Ashworth M (2000) When questionnaire response rates do matter: a survey of general practitioners and their views of NHS changes, *Br J Gen Pract*, 50: 479–480; Cockburn, J, Campbell, E, Gordon, J, Sanson-Fisher, R (1988) Response bias in a study of general practice, *Fam Pract* ,15 18–23 and Ashworth M (2001) When response rates do matter, *Br Med J*, 322: 675

few respiratory consultants responded to the request to take part. He responded:

“I’m not sure really. I think pretty much all respiratory consultants will be involved in some degree in these sorts of decisions because at the end of the day it is often respiratory system which is the cause of death or failure of the respiratory system. I’m not sure. I don’t know for sure how things work in other areas, in our hospital we are almost the gate keepers to ventilation, for children with severe neuro-disability because at the end of the day we are the people who end up looking after them and I think that is pretty much the same everywhere. I don’t know if doctors see themselves as rather tangential to these decisions and they are actually made in intensive care or by neurologists, but certainly in our institution it tends to be respiratory doctors who are fundamental to the final decision, so I don’t know sorry”

Dr 14 Respiratory Consultant

Sobal et al suggests a low response rate is not necessarily a problem when the questions are asked ‘of someone occupying a particular role about matters of concern in that role’ asserting that if there is uniformity amongst the people being asked the responses will be similar.⁴⁷¹ However, the difficulty here is not knowing the extent to which there is uniformity or whether there is something different about respiratory consultants which would mean their answers would be different. As there were sufficient responses from both PICU consultants and neurologists, it was possible, as shall be seen, to compare the responses from these two sub-specialties.

⁴⁷¹ Sobal, J, DeForge, BR, Ferentz, K. S, Muncie Jr, H., Valente, C M, Levine, DM (1990) Physician responses to multiple questionnaire mailings, *Evaluation Review*, 14(6), 711-722, p. 712

PART C – Analysing the data

12. Analysing the survey data

As was seen in chapter one⁴⁷² this thesis was strongly influenced by both Kennedy⁴⁷³ and the litigation concerning David Glass⁴⁷⁴ in the development of the research questions for this thesis. The impact of the author's personal experience was also acknowledged.⁴⁷⁵ The influence of the three paediatricians with whom the draft survey was piloted and discussed, was also described in part A of this chapter.⁴⁷⁶ For these reasons it would not be correct to say that grounded theory, as explained by Glaser and Strauss⁴⁷⁷ and more recently by for example Charmaz,⁴⁷⁸ was used as the research questions in this thesis were not developed just by the analysis of the data generated in the survey and semi-structured interviews conducted with doctors. However, the emerging data did go on to strongly influence the direction of the thesis. For example, in chapter one,⁴⁷⁹ it was seen that the choice of legal consciousness as the theoretical framework to explore what the doctors said about law and ethics emerged from the data. It will also be seen that 31 of the 33 doctors identified end of life decisions as the difficult ones they face, confirming this as the central focus of the thesis. Also, for example, as will be seen, the doctors'

⁴⁷² Chapter one, para 2, pp. 25-34, para 7, pp.60-70

⁴⁷³ Ian Kennedy, What is a Medical Decision? Astor Lecture, (Middlesex Hospital Medical School, London 1979). Also published in an amended form in Ian Kennedy, *Treat Me Right, Essays in Medical Law and Ethics*, (OUP 2001) 19-31

⁴⁷⁴ *Glass, R (On the application of) v Portsmouth Hospitals NHS Trust* (1999) EWCA Civ 1914; *Glass, R (On the application of) v Portsmouth Hospitals NHS Trust* (1999) EWHC Admin 343; *Glass v UK* (2003) ECHR Admissibility Decision no. 61827/00

⁴⁷⁵ Chapter one, para 5.2 pp. 12-20

⁴⁷⁶ Chapter three, para 4, pp. 108-109

⁴⁷⁷ Barney G. Glaser & Anselm L. Strauss, *The Discovery of Grounded Theory* (Aldine Publishing Company 1967)

⁴⁷⁸ Kathy Charmaz, *Constructing Grounded Theory* (SAGE Publications 2006)

⁴⁷⁹ Chapter one, para 1, p.1

sub-specialisms became Nvivo codes, as did themes raised across survey responses, such as advanced care plans or disagreements.

The survey data was analysed using the inbuilt Bristol Survey tools and Nvivo software. The Bristol survey tools allowed for the doctors' responses to both individual survey questions and to the survey as a whole to be considered. The tools also allowed for all the responses to a particular question or groups of questions to be analysed so that common themes, points of similarity and difference between doctors could be identified. Finally, the tools also allowed for particular combinations of responses to be compared. For example, a doctor's sub-specialism, age or parental status could be analysed alongside his or her response to whom the doctor involves in decisions or the weight the doctor puts on a child's cognitive impairment, if any, when making decisions.

The Nvivo software allowed for the survey data to be analysed in more detail. Nodes (the Nvivo term for codes) were first created drawing on the data by identifying repeated concepts in the doctors' survey responses. The researcher linked these to the relevant research question. The doctors' sub-specialisms were also coded, as were any references to best interests.

Figure 3: Nvivo codes based on research questions and sub-specialisms

overarching theme	sub-specialisms	RQ1	RQ2	RQ3	RQ4
best interests	emergency	colleagues	clinical	mentor	ethics
	endocrinology	conflict	cognitive ability	training & education	law
	general paediatrics	difficult decisions	involving the child		lawyer
	intensive care	emotions	nurses		public inquiries
	neonatology	parents	other professionals		rights
	Neurology	uncertainty	parents		withholding & withdrawing
	paed. surgery		prognosis		
	paed. oncology		quality of life		
	palliative care				
	respiratory				

As concepts emerged, the text was searched for direct mentions of any of the above terms or words or phrases that seemed to the researcher to be clear proxies. For example, references to benefits and burdens of treatment were coded as a reference to 'best interests'.

Additional nodes were added during the analysis of the survey data to group together comments made in the surveys by the doctors relating to: doctors' personal characteristics; comments doctors made about the use of advanced care/end-of-life plans; comments in relation to the question on resources; and any recommendations for improvements doctors made.

13. Interview recruitment

Doctors were asked to indicate in their survey responses whether they would be willing to discuss the issues raised in the survey further with the researcher. Twenty-two out of the thirty-three (66.6%) of the doctors indicated a willingness to further involvement with the study. Ultimately, semi-structured interviews were conducted with **nine** doctors, six males and three females. Three of the interviews were face to face and six were by telephone.

Of the thirteen other doctors who had indicated a willingness to be interviewed in their survey response, one doctor was not interviewed because she emigrated and could not be contacted. Another doctor died, and a third was removed from the GMC register. Six doctors did not respond to emails and the other six proved impossible to arrange interviews with the doctors within the time constraints of this thesis, due to their busy work schedules.⁴⁸⁰

⁴⁸⁰ The critical illness and death of the researcher's own son at this time also reduced the time available for interviews

Figure 4: Interviewee statistics

Doctors who completed survey	33
Doctors who indicated willingness to be interviewed	22
Doctors interviewed by telephone	6
Doctors interviewed face-to-face	3
Doctors who did not respond	6
Doctors who emigrated	1
Doctors who died	1
Doctors removed from GMC register	1
Doctors too busy	4

The nine doctors interviewed included doctors from the three key sub-specialisms, namely PICU, neurology and respiratory medicine, plus doctors from other sub-specialisms who could potentially provide an interesting comparison. They also included both male and female doctors and doctors from across the full potential age range for consultants. The doctors worked or had worked in all UK regions apart from Trent and Eastern.

Figure 5 Regions interviewees employed (current and past)

Note: This data is kept separate from other data in this thesis as some doctors could easily be identified if their region of work is revealed linked to other data. Note that a single doctor can appear in both columns and so the total is greater than nine, even though only nine were interviewed.

Region	No. Doctors Currently Employed	No. Doctors Previously Employed
Eastern	0	0
London	3	1
North & Yorkshire	1	1
North West	2	1
Northern Ireland	0	0
Scotland	0	1
South East	0	1
South West	1	2
Trent	0	0
West Midlands	1	0
Overseas	0	1

Figure 6 Sub-specialties, gender and age band of interviewees

Sub-specialism	Gender	Age band
Neurology	M	45-54
Neurology	M	55-64
Oncology	M	45-54
Respiratory	M	45-54
PICU	F	35-44
PICU	F	55-64
Neurology	F	55-64
Neurology	M	65-74
Palliative Medicine	M	45-54

14. **Conducting the semi-structured interviews**

Prior to each interview, each doctor was sent an email⁴⁸¹ reminding him or her of the nature of the research; how the data generated would be used and the steps, which would be taken to avoid identifying them. They were also told again of the ethical clearance obtained and again asked consent for the interview to be recorded. At the start of their interview all nine doctors were reminded this information and their consent again confirmed. As previously mentioned, they were also told that they could decline to answer any question; stop the interview at any time or leave the study at any time. The doctors were all told that the researcher would be transcribing the interviews and were all asked if they would like the transcribed interview sent to them for them to check, but none of the doctors took up this offer. As mentioned earlier, all the doctors had themselves been involved in academic research and all appeared to be very relaxed about the parameters of the research and, in particular, appreciated the difficulty of ensuring anonymity in a relatively small field of specialists.

The first three interviews were conducted face to face and the remaining six were conducted by telephone. The original intention was that all the interviews

⁴⁸¹ see Appendix 5, p.435

be face to face. There was concern that not doing so could lead to poorer data, especially as the opportunity to see the doctor's body language and facial expressions as they answered the questions put to them, would be lost. Like Stephens:⁴⁸²

'I suspected the medium would inhibit the establishment of rapport so essential for in depth qualitative interviewing. It would not allow space for probing and exploring questions.'⁴⁸³

However, when circumstances beyond the researcher's control dictated that the fourth and fifth interview be conducted by telephone, those interviews proved to be successful despite the anticipated potential limitations of this method.

The doctors appeared to find it easier to make time for the telephone interviews, particularly as they could be interviewed on days they were working from home or in the evenings from home. The doctors found they could give more time to the interview, particularly when they were being conducted away from their workplace. They were not constrained by clinical work and were free from interruptions. The doctors speaking from home appeared to speak more freely from the start of their interviews and to speak in much greater depth than those interviewed at work, but even those doctors talking by telephone from work appeared to be more candid than those interviewed face to face. The doctors interviewed face to face did all seem to become more relaxed and more candid as their interviews progressed. Holt⁴⁸⁴ suggests interviewees relax more when talking on the phone.⁴⁸⁵ The doctors talking by phone, even at work seemed more relaxed, especially at the start of their interviews. They were speaking from their office, away from their clinical environment, so seemed less

⁴⁸² Stephens, N, (2007) Collecting data from elites and ultra-elites: telephone and face-to-face interviews with macroeconomists, *Qualitative Research*, 7(2), 203-216

⁴⁸³ Ibid, p.205

⁴⁸⁴ Holt, A (2010) Using the telephone for narrative interviewing: a research note, *Qualitative Research* 10(1), 113-121

⁴⁸⁵ Ibid, p. 117

preoccupied, whereas those interviewed face to face chose to be interviewed, although in a private space, within their clinical environment. They were alert to potential interruptions should their work require this. This appeared to make the doctors on the phone more relaxed.

The doctors had been asked during email correspondence if they were happy to be recorded and again before the start of the interview, whether face to face or by telephone. All the doctors were very relaxed about being recorded. A digital recording app on a mini iPad was used to record all interviews. This was arguably less intrusive than a conventional digital recorder, especially as iPads and similar devices are now so commonplace. However, arguably those doctors talking on the phone were in part less reserved as they more quickly 'forgot' that their words were being recorded, than those sitting with the iPad in front of them.

As Holt found, interviewing by telephone

'enabled a far greater degree of control for the participants than a face to face interview may have. If I called at the agreed time and something had come up...there was no embarrassment or difficulty in re-arranging the appointment'.⁴⁸⁶

This happened with doctors asking to phone back, for example, half an hour or more later, with no detriment to the amount of time available for the interview. In contrast, when the start of one face to face interview was delayed as the doctor has held up in evening handover, the amount of time available to speak with that doctor was limited both by the doctor's need to get home and the researcher's need to catch a train. For this reason, it was decided to continue interviewing the doctors by telephone, rather than face to face.

A further advantage of interviewing by telephone was that as travel around the UK was not required, interviews could be conducted with doctors in different

⁴⁸⁶ Ibid, p.116

parts of the UK on consecutive days. This seemed to facilitate exploring common themes with doctors from one interview to the next much more easily, than when interviews were conducted with a significant time lapse between each, albeit with previous interviews being reviewed prior to each new interview.

Other researchers have also found that interviewing by telephone rather than face-to-face has not had a negative impact on their data when undertaking qualitative research. Sturges and Hanrahan suggest that when the topic is sensitive, as the subject of this thesis undoubtedly is, participants may prefer the relative anonymity of the telephone, increasing their sense of anonymity.⁴⁸⁷ Researchers who have compared telephone with face to face interviews 'have generally concluded that telephone interviewing was an acceptable and valuable method of data collection'.⁴⁸⁸ Bryman also suggests that interviewing by telephone rather than face-to-face may have the advantage that the researcher's personal characteristics, such as age, class and ethnicity is less likely to affect the interviewee's answers.⁴⁸⁹ Stephens⁴⁹⁰ suggests that this is particularly the case when the interviewees, are, as in this research, elites.

Although not a reason to continue interviewing by telephone, doing so also proved to have other benefits for the researcher. Conducting interviews by telephone considerably reduced the costs and time involved. It was also not necessary to arrange to interview doctors on set days or at set times, to fit in with the researcher's travel requirements.

⁴⁸⁷ Sturges JE, Hanrahan KJ, (2004) Comparing telephone and face to face qualitative interviewing: a research note, *Qualitative Research*, vol 4(1) SAGE Publications, London,107-118, p.108

⁴⁸⁸ Ibid, page 110

⁴⁸⁹ Bryman, A (2012) *Social Research Methods*, 4th Edition, Oxford University Press, New York, pp.214-215

⁴⁹⁰ Stephens N, (2007) Collecting data from elites and ultra-elites: telephone and face to face interviews with macroeconomists, *Qualitative Research*, vol. 7(2), SAGE Publications, London, 203-216

15. Analysing the interview data

The interview data was analysed using Nvivo software, initially using the same nodes as were used to analyse the survey data, listed in figure 3 above.⁴⁹¹

To facilitate the analysis of what the doctors said using legal consciousness theory, once the interview data had been classified using the nodes outlined above, interview data which seemed to reveal something about a doctor's legal consciousness was recoded using Nvivo software using the categories of legal consciousness developed by Ewick and Silbey,⁴⁹² Halliday et al⁴⁹³ and Harding⁴⁹⁴ as the Nvivo codes. This allowed the schema of legal consciousness exhibited by the doctors to be identified in accordance with existing legal consciousness schema. It also allowed for any gaps in the existing schema to be identified; namely any categories of legal consciousness exhibited by the doctors, which did not appear to the researcher to fit into existing schema, thus indicating whether additional schema are needed

Figure 7: Nvivo Codes: categories of legal consciousness

Ewick & Silbey schema	Halliday et al schema	Harding Schema
before the law	law as a sword	stabilising resistance
with the law	law as a shield	moderating resistance
against the law	law as a barrier	fracturing resistance
	collective dissent	

To enable classification of the doctors' observations into existing legal consciousness schema, key characteristics of each schema, as described by

⁴⁹¹ Chapter three, figure 3, p.125

⁴⁹² Ewick, P, Silbey, SS, (1992) Conformity, Contestation and Resistance: An Account of Legal Consciousness, *New Eng. L. Rev*, Vol. 26

⁴⁹³ Halliday, S, Kitinger, C, Kitinger, J, (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74

⁴⁹⁴ Harding, R, (2010), *Regulating Sexuality: Legal Consciousness in lesbian and gay lives*, Routledge, Abingdon

the schema's authors, were identified and doctors' comments expressing any of these were classified as being within that schema:

Figure 8: Characteristics attributed to Ewick and Silbey's schema

Before the law	With the law	Against the law
Remote, kept at a distance, grand, imposing, lawyers in control, set locations, dehumanising, objective, impartial, hierarchy, gate-keepers.	Present in every-day life, empowering, accessible, helps to achieve aims, game, tool, knowledge & expertise, more accessible to some than others, lawyers as go-betweens.	Net, traps ordinary people, need to struggle for freedom, resistance, untrustworthy, to be avoided, arbitrary, capricious, dangerous.

Figure 9: Characteristics attributed to Halliday et al's schema

Law as a sword	Law as a shield	Law as a barrier	Collective dissent
Power, weapon, disconnected from justice, used for personal gain.	Respect for law's power, deference, frustration at slowness, respect for impartial and powerful force, protective.	Struggle & resistance against power of law.	State law illegitimate, oppressive, resisted and subverted by their collective efforts.

Figure 10: Characteristics attributed to Harding's schema

Stabilising resistance	Moderating resistance	Fracturing resistance
Challenges power, not through deliberate acts but by being oneself outside of the norm.	Openly challenging the status quo e.g. through public demonstrations.	Acts of resistance requiring immediate or almost immediate action by the state.

16. Study Limitations

The following limitations were recognised as the data was being analysed.

- i) Only one respiratory consultant and one respiratory specialist registrar,⁴⁹⁵ opted to take part in this study.
- ii) The doctors who opted to take part, especially those who opted to be interviewed, all indicated that they were particularly interested in the subject matter of this study and as was seen earlier⁴⁹⁶ indicated they were pleased this study was being done. It is recognised that it is

⁴⁹⁵ Junior doctor at the end of her training specialising in paediatric respiratory medicine.

⁴⁹⁶ Chapter one, para 5.2, p.16

possible that the doctors are atypical of paediatricians making best interest decisions for disabled children generally.

- iii) As will be seen in the next chapter, a disproportionate number of male doctors opted to take part in the study compared with female doctors. This made an examination of the impact of gender on decision-making difficult.
- iv) As will also be seen in the next chapter, a surprising number of doctors with a personal connection with disability, especially doctors who are parents of disabled children themselves, took part in this study. However, it is recognised that discussing this personal characteristic in connection with any other personal and particularly any professional characteristic of the doctor, is likely to make the identity of doctors concerned too easily identifiable to colleagues. This has meant this personal characteristic which is potentially an important one in the context of this study, is not as explored as fully as the characteristic merits.
- v) Only one respiratory consultant chose to take part in the study, this means it was not possible to compare the responses of respiratory consultants, as one of three sub-specialisms often involved in end-of-care decisions for disabled children, with those of neurologists and PICU consultants, the other two sub-specialisms.
- vi) As will be seen in the next chapter, the doctors who responded to this study are not very diverse. However, it seems likely that this reflects the population under study, rather than a limitation of this study and a reflection of their elite status.
- vii) A strength of this study is that the respondents were mostly senior paediatric consultants in positions of influence with regard to best interest decisions for disabled children regionally and nationally. However, this is also a limitation of this study. The respondents tend to be doctors who have been qualified for many years, with all but one doctor, being consultants. This study therefore does not reflect

the thoughts and observations of junior doctors who have qualified more recently.

Having presented and explained the methodology used in this study, the next four chapters in this thesis focus on the voices of the doctors, presenting the empirical data from surveys and interviews conducted with UK paediatricians with the aim of addressing the research questions in this thesis.

PART TWO

Chapter Four

Who are the doctors in this study; what decisions do they find difficult; what makes those decisions difficult, and what factors do they consider when making difficult decisions for disabled children?

1. Introduction

This chapter, presents data from the study survey explaining who the doctors are in this study. It also addresses research question one, again drawing on data from the study survey, answering which decisions paediatricians find particularly difficult when working with severely disabled children and what makes those decisions particularly difficult? In answering both these questions the existing lenses discussed in chapter two⁴⁹⁷ are drawn upon to analyse what the doctors wrote in their survey responses. The debate started by Kennedy in 1979⁴⁹⁸ ('the Kennedy debate'), best interest decision-making as defined by the English High Court from *Re B (A Minor)* [1981]⁴⁹⁹ onwards and the doctors' professional ethical guidance are used as benchmarks for this analysis. The first part of research question two, is also addressed in this chapter, again using data from the doctors' survey responses, to answer what factors the doctors take into consideration when making difficult decisions for disabled children? The existing lenses found in chapter two are also used to evaluate these responses. The second part of research question two, the weight the doctors

⁴⁹⁷ Chapter two, pp. 23-94

⁴⁹⁸ Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form in Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

⁴⁹⁹ *Re B (A Minor) (Wardship, Medical Treatment)* [1981] WLR 1421 CA, August 1981

put on these factors when working with severely disabled children is addressed in the next chapter.⁵⁰⁰

This and the next chapter consider the extent to which there is consensus amongst doctors as to how decisions both should and are made. This is an important question because if doctors seem to decide unilaterally how to make best interest decisions, as opposed to, deciding in keeping with their professional guidance and the jurisprudence of the English High Court, the concerns explored in the Kennedy debate⁵⁰¹ seem all the more valid. It would then seem that there is little or no oversight as to how doctors decide a child's best interests. There would be nothing, for example, to stop a doctor deciding a child should not receive PICU treatment due to some random rule created by the doctor. If, however, doctors are making best interest decisions as recommended by the courts and their professional bodies, a way tested in earlier legal cases and carefully consideration by a professional body, then Kennedy's concerns seem less pressing.

This chapter starts by defining the term '*clinical factors*'. This is to contextualise what the doctors say about how difficult decisions are made for disabled children in the context of the on-going Kennedy debate. As was seen, Kennedy identified that '*medical decisions*' namely, decisions taken by doctors, can encompass both clinical factors - seen as being legitimately within the unique expertise and experience of a doctor - and non-clinical factors, which are arguably outside this realm. An understanding of what is meant by '*clinical factors*' is therefore important when considering the responses of the doctors in this study.

⁵⁰⁰ Chapter five, pp.181-236

⁵⁰¹ Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form in Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

Before turning to the doctor's responses, the doctors' professional guidance is briefly revisited. This is to help contextualise the doctors' responses and compare how the guidance says difficult decisions for disabled children should be made, with how the doctors say they and their colleagues actually make these decisions.

A summary of the profiles of the doctors, giving key demographic details is presented. Details are given of the doctors' gender, age, ethnic origin, places of work and training, paediatric sub-specialties, duration of practice, personal experience of disability, and faith. As mentioned in the last chapter, data that could make an individual doctor identifiable is not included.

This chapter then presents what types of decisions doctors say they find difficult and what they say makes those decisions particularly difficult. It then explores how the doctors make these decisions. The doctors' responses are then analysed in the context of the doctors' professional and personal characteristics, the aim being as far as is possible within the parameters of this study, to ascertain what influences individual doctors' decisions and the impact, if any, of individual doctors' personal or professional characteristics on their decision-making for disabled children.

2. Defining a clinical factor

The distinction between '*clinical*' and '*non-clinical*' factors gets to the heart of the on-going Kennedy debate started almost 40 years ago, as to which decisions are or should be within the assumed unique competence of a doctor. This question is pertinent to this thesis especially because, as shall be seen in this and later chapters, some of the doctors in this study voiced concerns, some strongly, that there are non-clinical factors doctors should *not* be considering when deciding for disabled children. Other doctors in this study had no such concerns and indeed said they put great weight on those very same factors when making decisions for disabled children. Defining '*clinical factors*' is therefore important.

In this thesis '*clinical*' is used to refer to a decision founded on actual observation by, and treatment of, the patients by health professionals.⁵⁰² It is distinguished from what might be termed a wider '*medical decision*' consisting of factors wider than just clinical ones. An assessment that a child has a poor quality of life, is happy at school, or has a worthwhile relationship with his or her family are classified as '*non-clinical decisions*'. As discussed in chapter two,⁵⁰³ Kennedy⁵⁰⁴ illustrated that the term '*medical decision*' can unhelpfully mean no more than a decision taken by a doctor. In this thesis, the term '*clinical*' is used to mean factors relating to the child's diagnosis, prognosis, and current clinical assessment. For example, whether a child has pneumonia,⁵⁰⁵ a tumour,⁵⁰⁶ respiratory distress⁵⁰⁷ or perhaps a raised lactate⁵⁰⁸ or a raised C-reactive protein test result.⁵⁰⁹

⁵⁰².www.medical-dictionary.thefreedictionary.com

⁵⁰³ Chapter two, para 2. pp. 25-34

⁵⁰⁴ Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form in Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

⁵⁰⁵ Defined as '*inflammation of the lung caused by bacteria, in which the air sacs (alveoli) become filled with inflammatory cells and the lung becomes solid.*' Source: Oxford Concise Medical Dictionary (2014); Oxford University Press, Oxford

⁵⁰⁶ Defined as '*any abnormal swelling in or on a part of the body. The term is usually applied to an abnormal growth of tissue, which may be benign or malignant*' Source: Oxford Concise Medical Dictionary (2014); Oxford University Press, Oxford

⁵⁰⁷ Defined as '*severe difficulty in achieving adequate oxygenation in spite of significant efforts to breathe: it is usually associated with increased respiratory rate and the use of accessory muscles in the chest wall. It can occur in both obstructive and non-obstructive lung conditions.*' Source: Oxford Concise Medical Dictionary (2014); Oxford University Press, Oxford

⁵⁰⁸ A test undertaken '*to help detect and measure the severity of low levels of oxygen in the body (hypoxia) and also lactic acidosis.*' Source: Association of Clinical Biochemistry & Laboratory Medicine; <http://labtestsonline.org.uk/understanding/analytes/lactate/tab/test/>; last accessed 2 July 2017

⁵⁰⁹ Defined as '*a protein whose plasma concentrations are raised in infections and inflammatory states and in the presence of tissue damage or necrosis*': Source: Oxford Concise Medical Dictionary (2014); Oxford University Press, Oxford

'Clinical factors' can be compared with 'non-clinical factors'. These include factors such as: whether a child is happy; a parent's ability to cope; the child's ability to interact with those around him or her; the child's quality of life and level of understanding; the child's school environment and the allocation of NHS resources. Although there is debate as to the extent to which any aspect of medical opinion can be objective,⁵¹⁰ another way of distinguishing between the clinical and non-clinical factors is that the clinical ones are those which it is easier to describe as objective, in that they can be scientifically established or tested by a doctor, such as a blood test; MRI scan or other investigation. Moreover, such factors are verifiable and repeatable by others using similar methods or approaches. In contrast, non-clinical factors require subjective evaluation and judgment, such as an assessment of the child's happiness; quality of life or even ability to interact and communicate. These factors are more difficult to quantify, let alone 'repeat' accurately in any consistently verifiable fashion. Clinical and non-clinical factors can also be distinguished as clinical being factors doctors are explicitly taught to assess in their biomedical education and training, while non-clinical are factors are not explicitly covered in this education. This is not to say, however, that elements of subjectivity do not form part of medical education and training, but they are rarely overtly acknowledged.

Before looking at the data, a second issue that it is helpful to address now is how their professional bodies guide doctors to make difficult decisions,⁵¹¹ as

⁵¹⁰ see for example Hayatt, MA, (2007) *Cancer Imaging: Lung & Breast Carcinomas*, Volume 1, Academic Press, p.48 (Subjective nature of interpretation of cancer imagining) & McClatchey, KD, (2002) *Clinical Laboratory Medicine*, Lippincott, Williams & Wilkins, p. 814 (subjective interpretation of blood samples)

⁵¹¹ A presumption can perhaps be made that while doctors may or may not be expected to be aware of legal cases which set out how, for example, best interest decisions, it is perhaps reasonable to expect a doctor to be aware of guidance from the General Medical Council which the GMC itself says '*all doctors are required to be familiar,*' and a consultant paediatrician to be aware of guidance pertinent to his or her sub-specialism from the RCPCH

this is the second existing lens through which what the doctors in this study said is analysed.

3. What does medical professional guidance say about decision-making for children?

The guidance produced by the RCPCH⁵¹² on withholding and withdrawing treatment for children was discussed in chapter two,⁵¹³ being one of the landmarks in best interest decision-making for disabled children. It is, however, worthwhile briefly repeating the main points of that professional guidance here, because it sets the UK benchmark for best practice for paediatricians when making difficult decisions for disabled children. As UK registered doctors, the participants in this study also have a professional duty to follow guidance produced by the GMC. Therefore, what that guidance says about best interest decision-making for children is also considered here.

As was seen in chapter two,⁵¹⁴ at the date the doctors were surveyed RCPCH 2004⁵¹⁵ was in place, providing the normative framework for best interest decisions for paediatricians. RCPCH 2004 gives express guidance with regard to disabled children, warning paediatricians against devaluing disabled children's lives, stating that a life with impairment is not incompatible with a life of quality and that disabled children should be provided with high quality health

⁵¹² RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London

⁵¹³ Chapter two, para 6 p.52-61

⁵¹⁴ Ibid

⁵¹⁵ RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London

care.⁵¹⁶ As was also seen in chapter two,⁵¹⁷ paediatricians are further guided to ‘avoid over pessimistic views about life with disability’⁵¹⁸ and to be aware that a disabled person’s view of quality of their life can differ from a non-disabled person’s view of life with impairment.⁵¹⁹ The guidance, as was seen earlier, suggests five scenarios where the RCPCH’s law and ethics committee judged a doctor might consider withholding or withdrawing treatment.⁵²⁰ As UK registered doctors, the doctors in this study would also be expected to follow the GMC’s ‘0-18 years: guidance for all doctors’ published in 2007 (‘GMC 2007’).⁵²¹

GMC 2007 guides doctors as to how they should practice when working with children. In a letter to the assistant clerk of the Public Petitions Committee of the Scottish Parliament dated 14 January 2014, the GMC’s Scottish Projects Officer set out the status of GMC guidance.⁵²² The Officer stated:

‘Good medical practice sets out the principles and values on which good practice is founded and all doctors are required to be familiar with and follow the guidance in GMP and our explanatory guidance on a range of issues. If a doctor seriously or persistently breaches the guidance we act to protect patients, if necessary removing the doctor from the register, or restricting or removing their right to practice medicine’.⁵²³

⁵¹⁶ RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London para 2.7.1, p. 24

⁵¹⁷ Chapter two, para 6 p.49-57

⁵¹⁸ RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London para 2.7.2 p. 24

⁵¹⁹ RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London para 2.7.2, p. 27

⁵²⁰ RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London, p.11

⁵²¹ GMC (2007) ‘0-18 Guidance for all doctors’, GMC, London

⁵²² GMC (2014) *Letter dated 14th January 2014 from Jackie Bell, Scottish Projects Officer GMC to Andrew Howlett, Assistant Clerk, Public Petitions Committee, Scottish Parliament*, http://www.gmc-uk.org/GMC_response_to_the_consultation_on_the_Scottish_Parliament_Public_Petitions_Committee_58721416.pdf, last accessed 20th June 2017

⁵²³ Ibid

GMC 2007 tells doctors that a child's best interests should be the doctor's guiding principle when deciding for a child.⁵²⁴ It recognises that identifying an individual child's best interests may not be an easy task:

'Doctors should always act in the best interests of children. This should be the guiding principle in all decisions, which may affect them. But identifying their best interests may not always be easy.'⁵²⁵

GMC 2007 (see figure 11 below) also guides the doctors as to how to assess a child's best interests.⁵²⁶

Figure 11: Paragraphs 12-13, GMC 0-18 Guidance (Source GMC) (footnotes omitted)

0-18 years guidance: Assessing best interests

12. An assessment of best interests will include what is clinically indicated in a particular case. You should also consider:

- a. the views of the child or young person, so far as they can express them, including any previously expressed preferences
- b. the views of parents
- c. the views of others close to the child or young person
- d. the cultural, religious or other beliefs and values of the child or parents²
- e. the views of other healthcare professionals involved in providing care to the child or young person, and of any other professionals who have an interest in their welfare
- f. which choice, if there is more than one, will least restrict the child or young person's future options.

13. This list is not exhaustive. The weight you attach to each point will depend on the circumstances, and you should consider any other relevant information. You should not make unjustified assumptions about a child or young person's best interests based on irrelevant or discriminatory factors, such as their behaviour, appearance or disability.

When analysing the data in this study, the extent to which doctors draw on clinical and non-clinical factors and seem to reflect in their actions RCPCH 2004 and GMC 2007 will be considered.

⁵²⁴ GMC (2007) '0-18 Guidance for all doctors', GMC, London, para 8

⁵²⁵ Ibid, para 8

⁵²⁶ Ibid, paras 12 & 13

Having established these preliminaries, the data from the doctors is now presented.

4. Doctors' Attributes

The personal attributes of the doctors in this study were of particular interest because a number of studies⁵²⁷ have found that characteristics attributable to the doctor as opposed to the patient's diagnosis, prognosis and clinical status can have a significant impact on doctors' difficult decisions. Among these studies, Cuttini et al⁵²⁸ and Richer et al⁵²⁹ have involved doctors from different nation states and have found, based on the same hypothetical scenarios, doctors from different states make different treatment decisions for the same patient. This suggests that the doctors' training, education, socio-economic factors and as far as they can be separated from other factors, their personal beliefs, are potentially influencing the treatment doctors give, rather than just characteristics intrinsic to the patient and their medical condition. For example, Richter et al⁵³⁰ found significant differences between Swedish, German and Russian doctors when presented with a series of hypothetical scenarios concerning the care of an 82-year-old patient with Alzheimer's and an acute life-

⁵²⁷ See for example: Cuttini, M, Nadai, M, Kaminski, M, Hansen, G, de Leeuw, Lenoir, S, Persson, J, et al (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries, *The Lancet* 355.9221: 2112-2118; Richter, J, Eisemann, M, Zgonnikova, E, (2001) Doctors' authoritarianism in end-of-life treatment decisions. A comparison between Russia, Sweden and Germany. *Journal of Medical Ethics*, 27(3), 186-191 & Mebane, EW, Oman, RF, Kroonen, LT, Goldstein, MK (1999) The Influence of Physician Race, Age, and Gender on Physician Attitudes Toward Advance Care Directives and Preferences for End-Of-Life Decision-Making, *Journal of the American Geriatrics Society*, 47(5), 579-591

⁵²⁸ Cuttini, M, Nadai, M, Kaminski, M, Hansen, G, de Leeuw, Lenoir, S, Persson, J, et al (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries, *The Lancet* 355.9221: 2112-2118

⁵²⁹ Richter, J, Eisemann, M, Zgonnikova, E, (2001) Doctors' authoritarianism in end-of-life treatment decisions. A comparison between Russia, Sweden and Germany. *Journal of Medical Ethics*, 27(3), 186-191

⁵³⁰ Ibid

threatening condition. They also found doctors decided differently when making decisions such as whether to give cardiopulmonary resuscitation and whether to follow a patient's known wishes, depending on the age, gender and length of practice of the doctor. In their United States study, Mebane et al⁵³¹ found significant differences in the end-of-life decisions made by white and black doctors when controlling for age and gender. Cuttini et al's (2000)⁵³² study of 1,235 neonatologists in eight European states, including the UK, which asked neonatologists to complete a survey concerning their practices when making end of life decisions, like Richter et al found variations in practice, in their study, both between states and between doctors within a single state. Cuttini et al report:

'Age, length of professional experience, and the importance of religion in the physicians' life affected the likelihood of reporting of non-treatment decision'.⁵³³

Earlier studies have therefore found that factors as varied as a doctor's age, gender, place of training, ethnic origin and religion seem to influence whether a doctor withheld, withdrew or gave treatment in life critical situations involving both infant and adult patients.

The present thesis is conducted on a small scale, so there is insufficient data to claim a direct influence between a particular personal or professional attribute and a particular attitude or way of behaving towards disabled children on the part of the doctor, even if all the doctors in the study with a particular attribute act in one way and all the other doctors act differently. It is, however, perhaps possible to say that data suggests that particular personal or professional

⁵³¹ Mebane, EW, Oman, RF, Kroonen, LT, Goldstein, MK (1999) The Influence of Physician Race, Age, and Gender on Physician Attitudes Toward Advance Care Directives and Preferences for End-Of-Life Decision-Making, *Journal of the American Geriatrics Society*, 47(5), 579-591

⁵³² Cuttini, M, Nadai, M, Kaminski, M, Hansen, G, de Leeuw, Lenoir, S, Persson, J, et al (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries, *The Lancet* 355.9221: 2112-2118

⁵³³ Ibid, p.2112

attributes may lead to a tendency on the part of the doctors to behave in a particular way and that a larger study would be merited.

A descriptive summary of key professional and demographic data for the study participants is included in figure 12. Key characteristics are used, for example doctors age, gender, parental status when analysing the data provided by the doctors. Why each characteristic is chosen is explained throughout the presentation and analysis of the data.

This page is intentionally blank

Figure 12: Professional and demographic profiles of study survey participants

Dr	Sub-specialism	Gender	Age band	Decade qualified	Parent	Lived outside UK for 1 Yr. +	Trained outside UK	Worked outside UK	Ethnic Origin	Has religious faith
1*	Neurology	M	45-54	1980s	YES	YES	NO	NO	White British	YES
2	PICU	F	45-54	1980s	YES	YES	YES	YES	White British	YES
3	General Paeds	?	45-54	1980s	YES	NO	NO	NO	White British	NO
4	Endocrinology	M	45-54	1980s	YES	NO	NO	NO	British	NO
5	General Paeds	M	55-64	1970s	YES	YES	NO	NO	White British	YES
6	Paediatric Surgeon	M	55-64	1970s	YES	YES	YES	YES	White British	?
7*	Neurology	M	55-64	1970s	YES	NO	NO	NO	White British	YES
8	Metabolic	M	45-54	1980s	YES	NO	NO	NO	White British	YES
9	Neurology	M	45-54	1980s	YES	NO	NO	NO	White British	YES
10*	Oncology	M	45-54	1980s	YES	YES	YES	YES	White British	YES
11	PICU	M	45-54	1990s	NO	YES	NO	YES	White British	NO
12	PICU	F	45-54	1980s	NO	YES	NO	YES	White British	NO
13	Resp. Registrar	F	35-44	1990s	NO	YES	NO	YES	White British	NO
14*	Resp.	M	45-54	1980s	YES	NO	NO	NO	White British	NO
15	PICU	?	45-54	1980s	YES	YES	YES	YES	?	YES
16	PICU	M	45-54	1990s	YES	YES	YES	YES	European	YES
17*	PICU	F	35-44	1990s	NO	YES	NO	NO	White British	NO
18*	PICU	F	55-64	1980s	NO	YES	YES	YES	Asian	YES
19	Neurology	M	55-64	1970s	YES	NO	NO	NO	White British	YES
20	General Paediatrics	?	45-54	1980s	NO	YES	YES	YES	?	NO
21	Neonatology	M	35-44	1990s	YES	NO	NO	NO	White British	NO
22	Neurology	F	?	1990s	YES	YES	YES	YES	European	YES
23	Neurology	M	45-54	1980s	YES	NO	NO	NO	White British	NO
24*	Neurology	F	55-64	1970s	YES	YES	NO	NO	White British	YES
25	Endocrine	M	45-54	1980s	YES	NO	NO	NO	White British	NO
26	Emergency	F	45-54	1980s	YES	NO	NO	NO	White British	NO

27	General Paeds	M	45-54	1980s	YES	YES	YES	YES	White British	YES
28	PICU	M	35-44	1980s	YES	NO	NO	NO	White British	YES
29*	Neurology	M	65-74	1960s	YES	NO	NO	NO	White British	YES
30	Neurology	M	45-54	1980s	YES	NO	NO	NO	White British	YES
31	PICU	F	45-54	1980s	NO	NO	NO	NO	White British	YES
32*	Palliative Medicine	M	45-54	1980s	NO	NO	NO	NO	?	YES
33	PICU	?	35-44	1990s	NO	YES	YES	YES	White British	NO

Key:

- Decade rather than date of qualification is given as doctors could too easily be identified from year of qualification
- Ethnic origin is presented in broad categories e.g. white British to avoid doctor being identified if precise ethnic origin provided
- Only parental status is presented and not whether individual doctor is a parent of a disabled child, to avoid identification
- Region is not presented as would make some doctors too easily identifiable
- Age is presented in a band to avoid a doctor being identified if exact age is given
- = interviewed
- ? = information not provided

4.1 Place of Work

The potential importance of culture on a doctor's attitudes and behaviours especially towards vulnerable patients was seen in chapters one and two,⁵³⁴ when both Bristol⁵³⁵ and Basnett's⁵³⁶ reflections on his medical training were discussed. Details of the doctors' places of work were therefore sought as it was anticipated that each place of work would have, to an extent, its own unique culture. Differences in workplace culture across the NHS are recognised.⁵³⁷ For such reasons, in the design of this research it was also important to know whether any of the doctors worked in the same hospital, particularly within the same sub-specialisms within that hospital, as if this occurred, comparisons could be made between the responses of doctors working within the same culture. The differences in culture across the NHS also made it important to ensure that the doctors in this study worked around the UK, not just in one hospital or region. If doctors did all work in the same place, this study would, to an extent, only tell us about how doctors make difficult decisions for disabled children in that hospital or region. If doctors from across the UK are saying similar things about their decision-making for disabled children, the doctors' responses can be generalised with much more confidence. Either way, the important and influence – or otherwise – of a workplace needs to be explored.

No doctor from a district hospital completed the survey. Self-evidently it is not possible to ask doctors who had chosen not to take part in research, why this

⁵³⁴ Chapter one, para 5.1, p.67, & chapter two, para 8, p.75

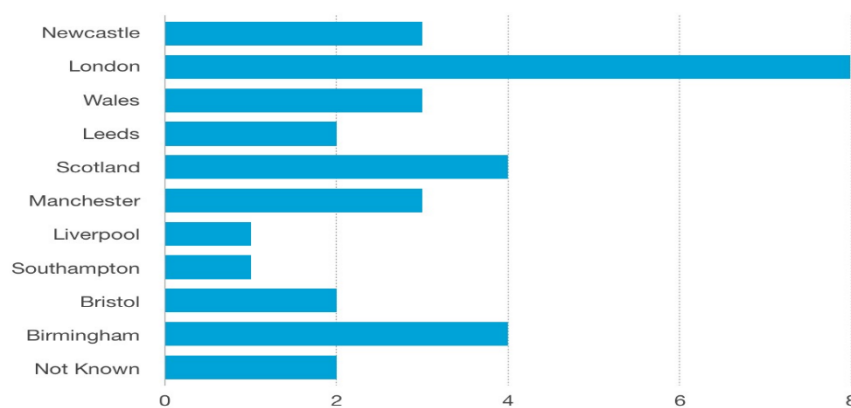
⁵³⁵ The Bristol Royal Infirmary Inquiry (2001), *The Inquiry into the management of care of children receiving complex heart surgery at the Bristol Royal Infirmary, Final Report*, Bristol Royal Infirmary Inquiry

⁵³⁶ Basnett, I, (2001) 'Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467

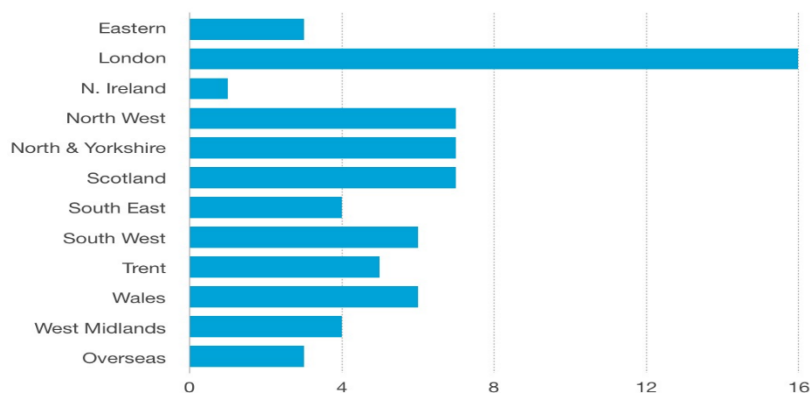
⁵³⁷ For example, Dixon -Wood M, et al (2016) *Culture and behavior in the English National Health Service: overview of lessons from a large multi-method study*, BMJ Qual Saf doi:10.1136/bmjqs-2013-001947, BMJ, London, last accessed 6th April 2016

was so, as part of that research. However, one possible reason why doctors from district hospitals did not choose to take part, is that the children who are the subject of this study have particularly complex health needs and so are more likely to have their healthcare provided by specialists in tertiary hospitals. PICUs are in tertiary hospitals. It is also where paediatric neurologists and respiratory specialists tend to work.

Figure 13: Places of work of participants at date of survey



The thirty-three respondents to the thesis survey included paediatricians working or having worked in every region of the United Kingdom. Twelve (36%) of the paediatricians reported having worked in just one NHS region throughout his or her career; the same number reported having worked in two NHS regions; six (18%) had worked in three NHS regions; three (9%) in four NHS regions and one (3%) in five regions. Three of doctors who had worked in more than one NHS region also reported having worked as a qualified doctor abroad, in either Canada or Australia.

Figure 14: Health regions in which participants have worked

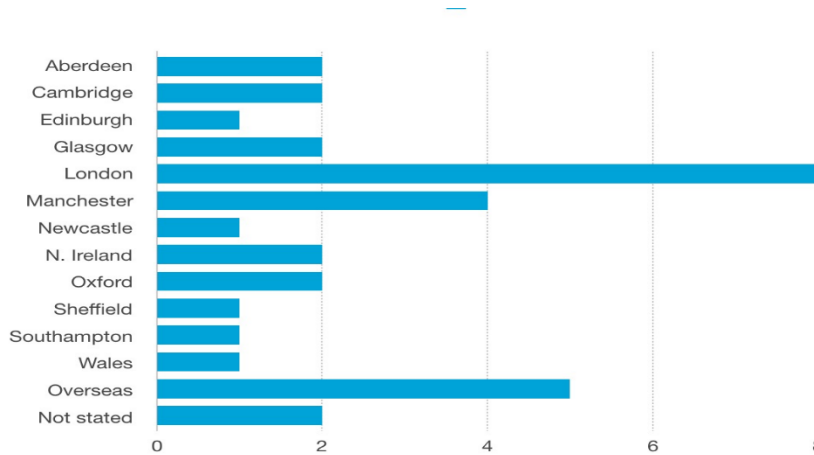
4.2 Place of undergraduate medical training

The doctors were asked where they had completed their undergraduate training. Five (15%) completed it in Scotland; nineteen (57%) in England; one (3%) in each in Wales and Northern Ireland and five (15%) overseas. This data was sought as medical training is not uniform throughout the United Kingdom. Different medical schools teach different syllabi; the doctors would also have encountered the different hospital cultures, just discussed and different attitudes from their teaching staff and when on their placements as medical students. All the doctors whose undergraduate training included any law and ethics completed their undergraduate training outside of England. Consideration is given in chapters eight⁵³⁸ and nine⁵³⁹ as to whether doctors with more or less training in law and ethics approach difficult decisions in different ways.

⁵³⁸ Chapter eight, pp.323-346

⁵³⁹ Chapter nine, pp.347-380

Figure 15: University undergraduate medical training completed



4.3 Overseas training and employment

The doctors were asked about any overseas medical training or employment. It was recognised that doctors who had trained or worked overseas will have been exposed to different cultures from those who had not done so and this may impact on how, a doctor approaches difficult decisions, for disabled children. Four doctors (12%) had completed part or all of their medical training abroad and five (15%) had worked as a qualified doctor outside of the UK. This compares with the GMC statistics of 37% of UK registered doctors in 2010 who had qualified overseas,⁵⁴⁰ but again this is a global figure for all UK doctors, with no breakdown available between consultants and junior doctors.

4.4 Sub-specialties

It was anticipated that doctors from different sub-specialisms may approach difficult decisions for disabled children differently, as doctors from the different sub-specialisms would have different experience of disabled children. Some of the sub-specialists are likely to see the child both when the child is ill in hospital and when the child is well at out-patient appointments. They will also attend (possibly over several years) multi-disciplinary meetings attended by a range of health; social care and educational staff, as well as the child's parent and in

⁵⁴⁰ GMC (2011) *The state of medical education and practice in the UK*, GMC, London, p.28

some cases the child him or herself, where many aspects of the child's life will be discussed. These sub-specialists are therefore likely to have a broad overview of the child, including non-medical aspects of the child's life. They may have long-term relationships with the children and their families. In contrast, other doctors will only ever see a disabled child when he or she is ill, in the case of PICU specialists, when the child is critically ill. These doctors are unlikely to have a long-term relationship with a child and will provide highly specialized care in a crisis. It therefore seems that doctors from different sub-specialisms may approach difficult decisions for disabled children from different perspectives. This makes it important for this study to classify doctors according to his or her sub-specialism. This forms an important part of the detailed analysis of the data in chapter five.⁵⁴¹

All the participants were paediatricians⁵⁴² and all but one⁵⁴³ were consultants.⁵⁴⁴ The doctors came from eleven different sub-specialties. Ten doctors (30%) were PICU consultants,⁵⁴⁵ nine (27%) were neurologists,⁵⁴⁶ four (12%) were

⁵⁴¹ Chapter five, pp.181-236

⁵⁴² Defined by the British Medical Association as '*Specialists in the medical management of conditions affecting babies, children and young people.*' Source: British Medical Association, (2016) *Doctors' Titles Explained*, BMA, London, p. 10

⁵⁴³ Dr.13 was a specialist registrar, defined by the British Medical Association as '*a junior doctor who has completed their foundation training but is still in training in a specialty area of medicine.*' Source: Source: British Medical Association, (2016) *Doctors' Titles Explained*, BMA, London, p. 3

⁵⁴⁴ Defined by the British Medical Association as '*a senior doctor who has overall responsibility for the care of patients in hospital. They have completed a minimum of six years training in their specialty area to gain a certificate of completion of training (CCT) and listing on the GMC's specialist register*' Source: Source: British Medical Association, (2016) *Doctors' Titles Explained*, BMA, London, p. 4

⁵⁴⁵ Doctors working in paediatric intensive care units caring for children when they are critically ill.

⁵⁴⁶ Doctors who treat children who have disorders of the brain, spinal cord, nerves and muscles or specialist in neuro-disability: www.rcpch.ac.uk/training-examinations-professional-development/postgraduate-training/sub-speciality-training/paedia-9, last accessed 9 March, 2016

general paediatricians⁵⁴⁷ and two (6%) were respiratory⁵⁴⁸ doctors.⁵⁴⁹ A further two doctors (6%) were endocrine⁵⁵⁰ specialists.

The remaining participants were a metabolic⁵⁵¹ specialist; an oncologist;⁵⁵² an emergency specialist;⁵⁵³ a neonatologist;⁵⁵⁴ and a surgeon.⁵⁵⁵

⁵⁴⁷ A hospital based doctor specialising in the care of children, although some will also specialise in a particular area of medicine, often they will be generalists, similar to a general practitioner in the community. Source: RCPCH, (2016), *Paediatric Sub-Specialty Glossary*, RCPCH, London <http://www.rcpch.ac.uk/training-examinations-professional-development/paediatric-careers-and-recruitment/careers/what-pae->, last accessed 16 June 2017

⁵⁴⁸ Doctors who deal with breathing and lungs. Source: RCPCH, (2016), *Paediatric Sub-Specialty Glossary*, RCPCH, London <http://www.rcpch.ac.uk/training-examinations-professional-development/paediatric-careers-and-recruitment/careers/what-pae-0>, last accessed 16 June 2017

⁵⁴⁹ One respiratory doctor was a consultant, the other was a specialist registrar, a junior doctor towards the end of her training.

⁵⁵⁰ Doctors who treat illnesses related to the hormones Source: RCPCH, (2016), *Paediatric Sub-Specialty Glossary*, RCPCH, London <http://www.rcpch.ac.uk/training-examinations-professional-development/paediatric-careers-and-recruitment/careers/what-pae-0>, last accessed 16 June 2017

⁵⁵¹ Doctors who treat inborn errors of the metabolism Source: RCPCH, (2016), *Paediatric Sub-Specialty Glossary*, RCPCH, London <http://www.rcpch.ac.uk/training-examinations-professional-development/paediatric-careers-and-recruitment/careers/what-pae-0>, last accessed 16 June 2017

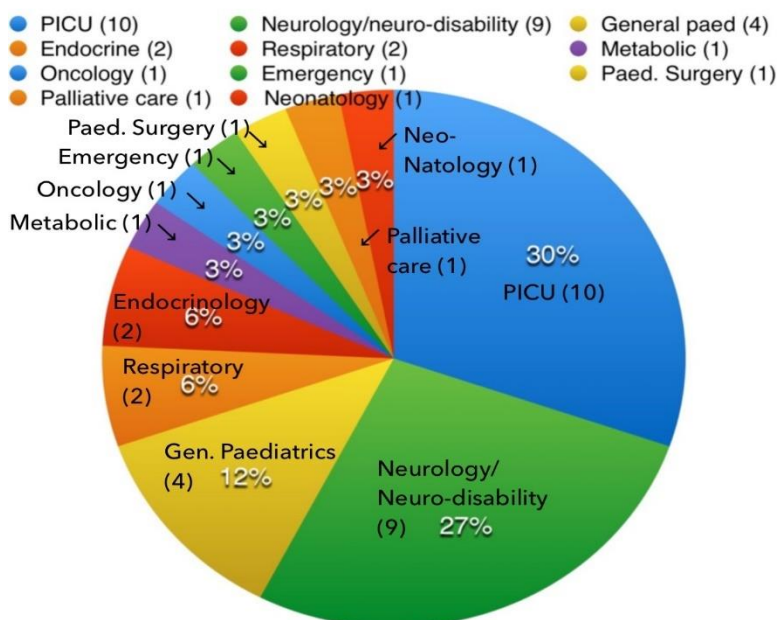
⁵⁵² Doctors who specialise in the treatment of cancer. Source: RCPCH, (2016), *Paediatric Sub-Specialty Glossary*, RCPCH, London <http://www.rcpch.ac.uk/training-examinations-professional-development/paediatric-careers-and-recruitment/careers/what-pae-0>, last accessed 16 June 2017

⁵⁵³ A doctor providing immediate treatment and care in an accident and emergency department. Source: RCPCH, (2016), *Paediatric Sub-Specialty Glossary*, RCPCH, London <http://www.rcpch.ac.uk/training-examinations-professional-development/paediatric-careers-and-recruitment/careers/what-pae-0>, last accessed 16 June 2017

⁵⁵⁴ Neonatologists specialise in the care of the sickest and most premature babies in neonatal intensive care units. Source: RCPCH, (2016), *Paediatric Sub-Specialty Glossary*, RCPCH, London <http://www.rcpch.ac.uk/training-examinations-professional-development/paediatric-careers-and-recruitment/careers/what-pae-0>, last accessed 16 June 2017

⁵⁵⁵ Specialists who treat disease through surgery. Source: RCPCH, (2016), *Paediatric Sub-Specialty Glossary*, RCPCH, London <http://www.rcpch.ac.uk/training-examinations-professional-development/paediatric-careers-and-recruitment/careers/what-pae-0>, last accessed 16 June 2017

Figure 16: Participants' paediatric sub-specialties



4.5 Duration of practice

The doctors were asked their duration of practice to enable a comparison to be made between doctors who qualified at different points along the time-line set out in chapter two. The doctors who responded to this survey include doctors who qualified in the 1960s and 1970s, prior to Kennedy's Astor lecture,⁵⁵⁶ the trial of Dr Arthur⁵⁵⁷ and *Re B*.⁵⁵⁸ The doctor who qualified most recently, a specialist registrar, did so the same year as the HRA received royal assent.⁵⁵⁹ This span allows for the doctors' responses to be analysed to see whether any patterns of answers emerge suggesting any changes in the way doctors approach best interest decisions for disabled children, from the different eras. One doctor (3%) qualified in the 1960s; five (15%) in the 1970s; twenty doctors

⁵⁵⁶ Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form in Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

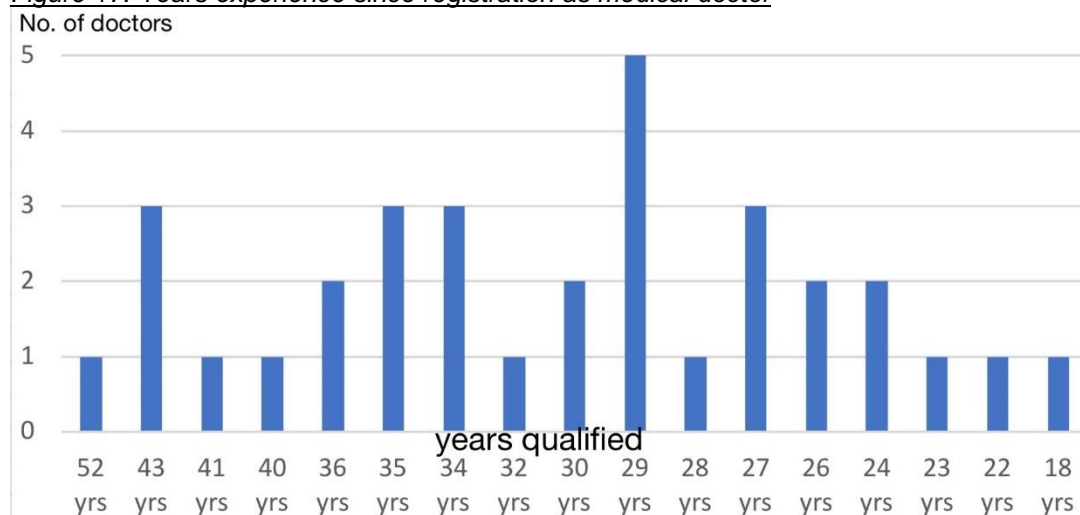
⁵⁵⁷ *R v Arthur (1981)* 12 BMLR 1, heard before Farquharson J, 3-5th November, 1981

⁵⁵⁸ *Re B (A Minor) (Wardship, Medical Treatment) (1981)* WLR 1421, CA, August 1981

⁵⁵⁹ Human Rights Act 1998 c 42

(60.5%) qualified in the 1980s and seven doctors (21%) qualified in the 1990s. Including the specialist registrar, the participants reported having between 18 and 52 years professional experience. Twenty-four doctors (72%) had been qualified between 24-36 years.

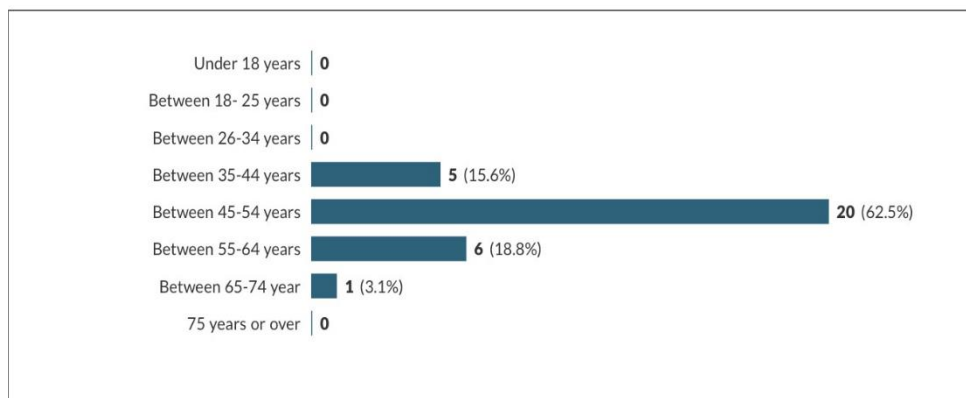

Figure 17: Years experience since registration as medical doctor



4.6 Age

The doctors were asked their age in addition to their duration of practice, recognising that doctors with the longest duration of practice were not necessarily those who were the eldest. Doctors were asked which age band they fell within rather than their precise age, as identifying a doctor's exact age may make the doctor identifiable. Twenty-one (63%) of the respondents overall (thirteen (65%) of the male respondents and four (44%) of the female respondents) reported being between 45-55 years old. The RCPCH reported an overall mean age of 48.8 for male consultants and 46.5 years for female consultants in 2009.⁵⁶⁰ The mean age of female and male doctors in this study is in line with that for paediatric consultants, as reported by the RCPCH.

⁵⁶⁰ RCPCH (2011) *RCPCH Medical Workforce Census for 2009*, RCPCH, London p. 42

*Figure 18: Participants' age*How old are you? 

4.7 Ethnic Origin

As was seen earlier,⁵⁶¹ Mebane et al⁵⁶² suggest that a doctor's ethnic origin may influence a doctor's decisions whether to withhold or withdraw treatment from patients. It will be recalled from chapter two⁵⁶³ that Whiteneck⁵⁶⁴ had found discriminatory attitudes towards disabled people amongst doctors, but identified a lack of data as to the doctors' personal characteristics as a weakness in his study. He recognised that these characteristics may influence doctors' attitudes and behaviours. This study therefore asked doctors their ethnic origin with the aim of exploring this as one characteristic, which may impact, on doctors' difficult decisions for disabled children.

The doctors were asked their ethnic origin using the UK standard classifications of ethnicity utilised in the English version of the UK census. The English rather than Scottish classifications were used as it was anticipated that most

⁵⁶¹ Chapter four, para 3, p.146

⁵⁶² Mebane, EW, Oman, RF, Kroonen, LT, Goldstein, MK (1999) The Influence of Physician Race, Age, and Gender on Physician Attitudes Toward Advance Care Directives and Preferences for End-Of-Life Decision-Making, *Journal of the American Geriatrics Society*, 47(5), 579-591

⁵⁶³ Chapter two, para 10, p. 85

⁵⁶⁴ Whiteneck, G, (1989) Long-term outlook for persons with high quadriplegia, in Whiteneck G, Adler C, Carter RE et al (eds) *The Management of High Quadriplegia*, Demos Publications, New York

respondents would be based in England, where the majority of paediatricians are located. This was borne out in the responses with twenty-five doctors (76%) being employed in England; four (12%) in Scotland and three (9%) in Wales. One doctor (3%) did not reveal his or her location. Doctors were asked to indicate their ethnic origin from the following list: English, Scottish, Welsh, Northern Irish, British, Gipsy/Traveller, Polish, European, Pakistani, Indian, Bangladeshi, Chinese, African, Caribbean, Arab, Mixed or multiple ethnic origins. The doctors could indicate that they were from one or more ethnic groups and also add a comment if they wished.

Twenty doctors (60.5%) identified themselves as ethnically English, Scottish, Welsh or from Northern Ireland. While recognising that a doctor may identify as being English, Scottish, Welsh or from Northern Ireland and not be white, it is thought likely that, for example, a doctor who is a third-generation immigrant would identify him or herself as having mixed or multiple ethnic origins or by listing all his or her ethnic origins (this option being available). This does tend to suggest that when compared with the population of doctors as a whole, the sample in this survey was disproportionately white, but not disproportionately so for consultants. The GMC recorded just 47.7% of UK registered doctors being ethnically 'white' as at 2010.⁵⁶⁵ Although 18.7% of UK registered doctors describe themselves as of Asian ethnic origin in the GMC's statistics,⁵⁶⁶ the statistics do not distinguish between consultants and junior doctors in their ethnic breakdown. The GMC do state, however, that the consultant workforce is 'still predominantly white'.⁵⁶⁷ In this study, just one doctor (3%), who described herself as Chinese, can based on this, be classified as Asian.

⁵⁶⁵ GMC (2011) *The state of medical education and practice in the UK*, GMC, London, p. 32

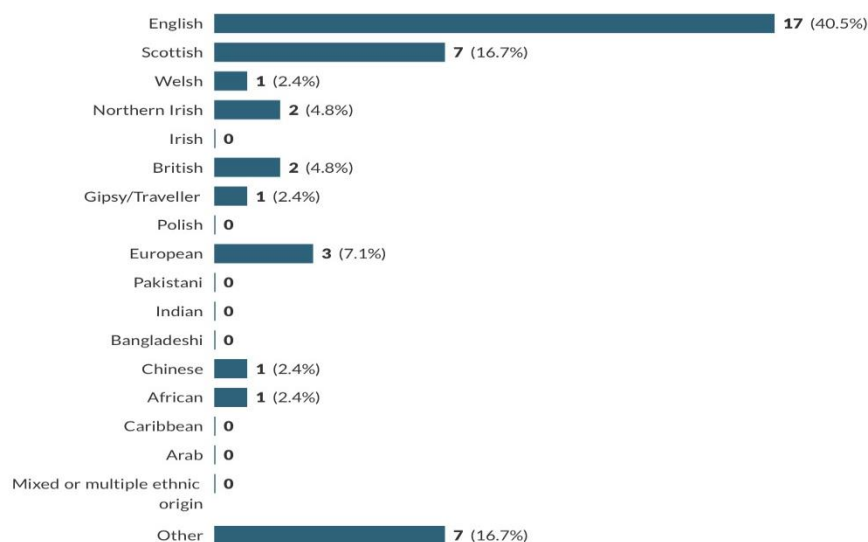
⁵⁶⁶ Ibid

⁵⁶⁷ Ibid, p. 36

Much is written about ‘the snowy white peaks’ of the NHS⁵⁶⁸ whereby despite having the most ethnically diverse workforce in the UK, those from ethnic minority backgrounds face significant difficulties in obtaining senior positions. Thirty-two doctors (97%) in this study, held senior clinical positions, some also senior managerial positions such as clinical director. The ethnic profile of the participants seems to reflect the underrepresentation of ethnic minorities within the senior ranks of the medical profession.

Figure 19: Participants’ ethnic origin

How would you describe your ethnic origin



Due to the lack of diversity amongst the doctors in this study, it was not possible to compare responses of doctors from different ethnic groups.

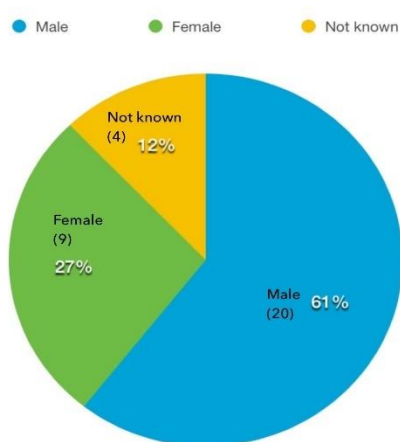
4.8 Gender

A doctor’s gender was also recognised as a factor that could potentially impact on how a doctor approached difficult decisions for disabled children. Twenty doctors (60.5%) identified themselves as being male and nine (27%) as being

⁵⁶⁸ See for example, Kline, R, (2014) *The ‘snowy white peaks’ of the NHS: a survey of the discrimination in governance and leadership and the potential impact on patient care in London and England*, Middlesex University, London and Priest, N, Esmail, A, Williams, DR, Sprague, Norman, F, Smart, Norman, L (2015) Promoting equality for ethnic minority NHS staff –what works?, *BMJ* 2015: 351: h3297

female. The remaining four doctors (12%) did not specify their gender. All the participants apart from Dr.13⁵⁶⁹ were on the GMC Specialist Register,⁵⁷⁰ which had 70% male and 30% female doctors in 2010.⁵⁷¹ The ratio of male to female doctors in this survey is therefore fairly similar to the ratio of male to female doctors on the GMC's Specialist register.

Figure 20: Participants' gender



The workforce census conducted by the RCPCH in 2009, however, indicates that 46.6% of paediatric consultants were female and 53.4% were male.⁵⁷² By the next RCPCH workforce census in 2011 the percentage of female paediatric consultants had risen to 48.6%.⁵⁷³ As noted earlier, the doctors in this study all worked in tertiary hospitals where the RCPCH workforce census indicate the ratio of female to male consultants is lower, with 39.6% of tertiary paediatric

⁵⁶⁹ A specialist registrar, a junior doctor in the last stage of training.

⁵⁷⁰ This is the GMC register of doctors eligible for appointment as a consultant. See http://www.gmc-uk.org/doctors/register/information_on_the_specialist_register.asp last accessed 12 June 2017

⁵⁷¹ GMC (2011) *The state of medical education and practice in the UK*, GMC, London, p.21

⁵⁷² RCPCH (2011) *RCPCH Medical Workforce Census for 2009*, RCPCH, London, p.41

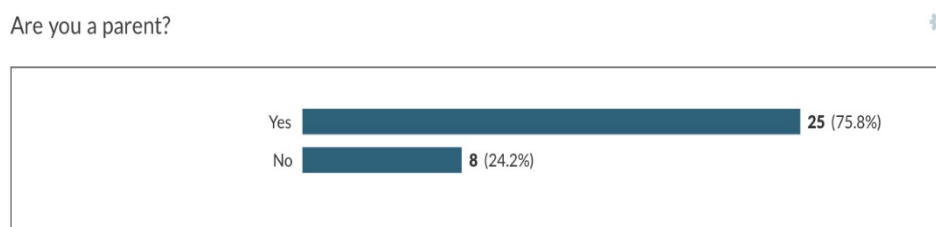
⁵⁷³ RCPCH (2013) *RCPCH Medical Workforce Census for 2011*, RCPCH, London, p.46

consultants being female in 2009⁵⁷⁴ and 43.9% being female in 2011.⁵⁷⁵ The doctors in this study were, for paediatricians, disproportionately male. One reason for this may be that, as the RCPCH reports, female consultants are more likely to be working part-time than their male colleagues, potentially giving them less work time for tasks such as completing this survey: RCPCH (2014) states that as at 2013, 35% of the female paediatric consultant workforce worked part-time, compared with 9.5% of male paediatric consultants.⁵⁷⁶

4.9 Parental status & personal experience of disability

Being a parent and have personal experience of disability were also seen as personal characteristics which could impact on how a doctor approached difficult decisions for disabled children. Twenty-five doctors (76%) in this study described themselves as a parent.

Figure 21: Participants' parental status



Ten doctors (30%) reported personal experience of disability; defined as the doctor being disabled him or herself, or having a close family member who was disabled.⁵⁷⁷ Six doctors (18%) reported this experience to be parenting a disabled child. Four (12%) reported having a disabled close relative other than their child. Two doctors (6%) did not answer the question. No doctor declared him or herself to be disabled.

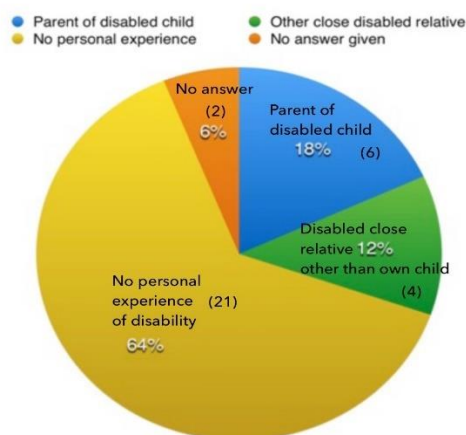
⁵⁷⁴ RCPCH (2011) *RCPCH Medical Workforce Census for 2009*, RCPCH, London, p.41

⁵⁷⁵ RCPCH (2013) *RCPCH Medical Workforce Census for 2011*, RCPCH, London, p.46

⁵⁷⁶ RCPCH (2014), *RCPCH Medical Workforce Census 2013*, RCPCH, London, Main Findings, p. 2

⁵⁷⁷ This category also allowed for doctors to identify him or herself as being disabled, but no doctor in this study did so.

Figure 22: Participants' personal experience of disability



UK government statistics report 0.8 million (6%) of children in the UK were disabled in 2010/2011,⁵⁷⁸ according to the Equality Act 2010 definition of disability.⁵⁷⁹ The number of doctors in this study who are parents of disabled children at 18%, is therefore unexpectedly high. Indeed, distribution of disability is not equal through UK society, as Graham reports:

‘socioeconomic inequalities in ill-health and disability typically take the form of a ‘social gradient’, in which those in higher socioeconomic groups have better health and fewer disabling conditions than groups below them’⁵⁸⁰

⁵⁷⁸ DWP (2012) *Family Resources Survey United Kingdom 2010/2011*, Department of Work & Pensions, London, p. 79, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/222839/frs_2010_11_report.pdf, last accessed 16 June 2017

⁵⁷⁹ s.6 Equality Act, 2010, c.15, Part 2, Chapter 2, ‘Disability

(1) A person (P) has a disability if—
 (a) P has a physical or mental impairment, and
 (b) the impairment has a substantial and long-term adverse effect on P’s ability to carry out normal day-to-day activities.’

⁵⁸⁰ Graham, H (2016) *Socioeconomic inequalities in health in the UK: Evidence on patterns and determinants*, A short report for the Disability Rights Commission, DRC, London, p. 4 <http://disability-studies.leeds.ac.uk/files/library/graham-socioeconomic-inequalities.pdf>; last accessed 7/7/16

The paediatric consultants in this study, being elites if not ultra-elites, as defined in chapter two,⁵⁸¹ can be seen as being on a par with the medical consultants identified by The Sutton Trust, namely being both a socially and economically very advantaged group.⁵⁸² It would, in the light of this and the reported decrease in the prevalence of disability with greater social and economic status, be expected that the prevalence of consultants who are parents of disabled children or have close family connections to a disabled individual, to be *lower* than the national average, not higher, as appears to be the case. Even if doctors as a group have an average number of disabled children, it is possible that the figure for doctors who are parents of disabled children is higher in this study, because doctors who are parents of disabled children were more motivated than others to respond to the request to join this study, due of their personal interest in disabled children. Doctors who were parents of disabled children who were interviewed did comment that they had been particularly drawn to the study due to their personal interest. The potential limitations this may create for this study are discussed in chapter ten.⁵⁸³

4.10 Religion or Faith

The study by Cuttini⁵⁸⁴ et al mentioned earlier⁵⁸⁵ found their religious faith impacted on neonatologists across Europe end-of-life treatment decisions whether to withdraw life sustaining treatment from neonates.⁵⁸⁶ It was therefore thought important to ask doctors in this study about their religious faith, if any, to

⁵⁸¹ Chapter three, para 2.2, pp. 99

⁵⁸² The Sutton Trust (2009) *The Educational Background of Leading Lawyers, Journalists, Vice Chancellors, Politicians, Medics and Chief Executives*, The Sutton Trust, Sutton, www.suttontrust.com/wp-content/uploads/2009/04/ST_MilburnSubmission.pdf, last accessed 7 July 2016

⁵⁸³ Chapter ten, para 4.4, p.398

⁵⁸⁴ Cuttini, M, Nadai, M, Kaminski, M, Hansen, G, de Leeuw, Lenoir, S, Persson, J, et al (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries, *The Lancet* 355.9221: 2112-2118

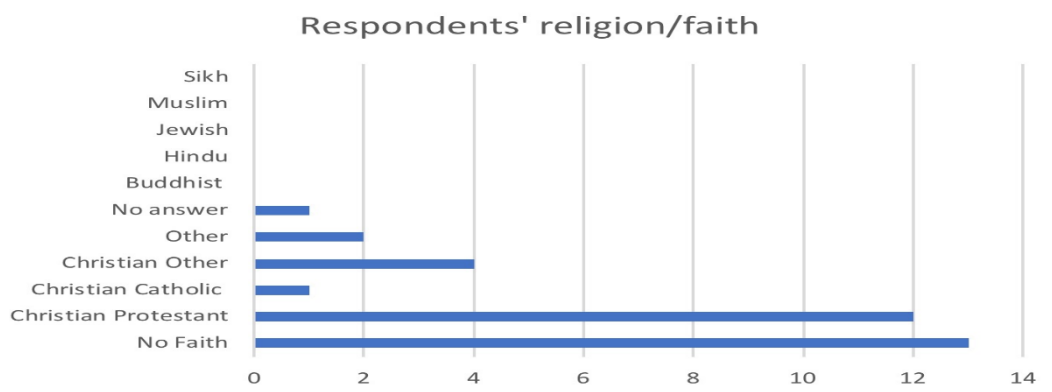
⁵⁸⁵ Chapter four, para 3, p. 145

⁵⁸⁶ Infant up to the age of 28 days

assess whether this seemed to impact on the doctors' difficult decisions for disabled children.

Nineteen doctors (57%) describe themselves as belonging to a particular religion or faith, predominantly Christianity. This is likely to reflect the ethnicity of the sample, being predominantly doctors who describe themselves as being white, English, Scottish, Welsh or British.

Figure 23: Participants' religion or faith



Key personal and professional characteristics established so far will be used in the next chapter to compare the decision-making of doctors. For example, a comparison will be made between female and male doctors; between doctors from the different sub-specialisms and between doctors who have personal experience of disability and those who do not, to see whether there is any suggestion that any of these personal or professional characteristics impact on how a doctor approaches difficult decisions for severely disabled children. Having established the doctors' personal and professional characteristics, consideration is now given to what sort of decisions they found difficult when working with disabled children and what made those decisions difficult.

5. Defining Difficult Decisions

It will be recalled from chapter two,⁵⁸⁷ that a description of the types of impairments and health problems the children who were of particular interest to this study, might be expected to experience were given to the doctors at the start of this study.⁵⁸⁸ Considerable thought was given whether to provide this information to the doctors. Merit was seen is leaving the doctors to define the types of impairments and health problems the children might have themselves, recognising that how a doctor described a child could say something not only about the doctor's approach to decision-making, but also about how the doctor conceptualised 'disability'. However, it was also recognised that, not only, as was seen in chapter two,⁵⁸⁹ are children often left out of the debate on disability,⁵⁹⁰ but also in real life situations when the needs of disabled children are being considered, those with the most severe impairment and complex health problems can be overlooked.⁵⁹¹ For, this reason, to ensure the doctors reflected on their treatment decisions for severely disabled children with complex health problems, some guidance as to the children of interest was provided for the doctors in the survey introduction.

The doctors were then asked in the survey: '*what sort of difficult decisions do you find yourself making when dealing with disabled children?*'

⁵⁸⁷ Chapter one, para 2.3, p.4

⁵⁸⁸ See Appendix 4, 427

⁵⁸⁹ Chapter two, para 9, p.80

⁵⁹⁰ Coker, M, Davis, JM (2000) 'Disabled Children (Still) Invisible Under the Law, in Cooper, J, *Law Rights and Disability*, Jessica Kingsley Publishers, London

⁵⁹¹ Whiting. M (2012) Impact, meaning and need for help and support: The experience of parents caring for children with disabilities, life threatening illnesses or technology dependence, *Journal of Child Health*, 17(1), 92-108, at p.94

5.1 The responses

Decisions whether to withhold or withdraw treatment when a disabled child was critically ill were, however, cited by thirty-one doctors (94%) as the sort of difficult decision he or she found themselves dealing with when working with disabled children. The two doctors who did not cite this scenario were Dr 6, a paediatric surgeon, and Dr 4, a paediatric endocrine consultant. These two doctors cited scenarios very specific to their sub-specialties. For Dr 6, this was the decision whether to agree to a parental request for a severely disabled Muslim boy to be circumcised for religious reasons. For Dr 4, it was whether treatment should be given to disabled children to, for example, delay menarche; to treat metabolic bone disease in a child or to give growth hormone to a child who uses a wheelchair. Because 94% of the study participants cited 'best interest' decisions to withhold or withdraw treatment as the difficult decisions they face, this is the focus of the rest of this study. This finding matches what was expected before this study started, based on the researcher's experience in the field, but had the doctors suggested different types of decisions were particularly difficult when treating disabled children this would have been reflected in the study's focus. As previously mentioned,⁵⁹² for the rest of this thesis the terms 'difficult decisions', 'best interest decisions' and 'end-of-life decisions' will now be used interchangeably.

5.2 Decisions to limit treatment

As mentioned, thirty-one doctors (94%) in the study cited decisions whether to withhold or withdraw treatment, as the difficult decisions they face when working with disabled children. Most of the doctors simply stated the decision, for example:

Dr 2

"Limitations of invasive care, one-way extubation, choice of palliative care route, decision to embark on intensive care at all"

⁵⁹² Chapter one, para 2.4, p. 6

Dr 22

“end of life decisions, i.e. withdrawal of acute care, change to palliative/terminal care”

Dr 26

“whether they should be offered PICU treatment and/or support, how aggressive to be with resuscitation”

Dr 32

“treat/don’t treat (e.g. ventilation)”

A few doctors expanded on their answers giving a greater insight into what made these decisions particularly challenging, (an issue explored with all the doctors in later questions). For example:

Dr 8

“How far to pursue hope of recovery from acute illness when a condition is known to be ultimately fatal. How aggressively should I intervene, for example, is invasive treatment such as intensive care appropriate? The point at which treatment becomes futile? At what point would I consider withholding a treatment? When do I have these discussions with the family? Will they think I just want to give up? Do I just want to give up? My own feelings, am I making a value judgment on ‘quality of life’, which I have no right to make? When do I suggest hospice care or terminal care? When and how do I have discussions about ‘do not attempt resuscitation’ orders? How often (or how repeatedly) do I bring this up? Some treatments of limited benefit are very expensive, should this concern me?”

and Dr 21

“We may have discussions about the appropriateness of continuing neonatal intensive care in the context of massive brain injury (on cranial ultrasound or MRI). We may decide in children with a ‘lethal’ congenital abnormality/disability that escalation of supportive care is not appropriate. We may have occasions when medical decisions are not supported by the family – this is rare.”

“Transition to palliative care/comfort care from intensive care can involve very difficult decisions largely due to the change in emphasis and adjustment of parental and team expectations.”

5.3 Why is withdrawing or withholding treatment mentioned so frequently?

As was seen earlier⁵⁹³ many of the doctors who took part in this study worked in sub-specialties where end-of-life decisions feature frequently, for example PICU, neurology,⁵⁹⁴ palliative care and oncology. This may explain why so many of the doctors raised the withholding/withdrawing of treatment as the most difficult decision they make, working frequently as they do with children with life limiting or life-threatening conditions.

For example, as was seen earlier, ten doctors (30%) were PICU consultants. Information as to how commonly children die in PICU is contradictory. The Paediatric Intensive Care Audit Network ('PICUNet'), which collects data on all children admitted into intensive care, reports:

'It is extremely rare for a child to die in paediatric intensive care and nearly 96% of children were discharged alive in 2008-2010'⁵⁹⁵

However, RCPCH 2015 states:

'Despite increased options for the provision of end-of-life care, many deaths still occur in hospital settings following decisions to withhold, withdraw or limit lifesaving treatment.'⁵⁹⁶

Arguably the RCPCH could be making a distinction between decisions to withhold or limit treatment where a child never enters PICU and decisions to withdraw treatment from a child in PICU. If this is the distinction being made, it

⁵⁹³ Chapter four, figure 4, p.157

⁵⁹⁴ Many of the conditions neurologists manage are life limiting, such as muscular dystrophy or other rare degenerative or life-threatening conditions such as meningitis and epilepsy. Many children with neuro-disability will also be prone to life threatening infections such as pneumonia meaning that like PICU consultants, they often deal with dying children.

⁵⁹⁵ Paediatric Intensive Care Audit Network (2011) *Annual report of the Paediatric Intensive Care Audit Network, January 2008- December 2010, Summary Report*, Universities of Leeds and Leicester, para 12, p. 11

⁵⁹⁶ Larcher, V, Craig, F, Bhogal, K, Wilkinson, D, Brierley, J (2015) 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice' *Archives of Disease in Childhood* 2015;100: s1-s23

suggests that a significant number of children do not access PICU and die, but very few (according to PICUNet) who enter PICU die. As will be seen in chapter six,⁵⁹⁷ several doctors in this study do voice their concerns that disabled children can be denied access to PICU in circumstances where those doctors believe the child would benefit from PICU care. Other consultants in this study voice their own reluctance to admit disabled children to PICU.

5.4 What makes these decisions difficult?

The doctors were next asked, '*what aspects of these decisions do you find most difficult?*' Doctors raised a range of difficulties, with several citing more than one. Seventeen doctors (51%) raised discussions or communicating with a child's parent as the aspect they found most difficult when dealing with difficult decisions. Perhaps it is noteworthy that the doctors did not talk about discussions with parents as being emotionally difficult, as perhaps might be expected, especially if doctors are having to discuss a child's potential death with a parent. It is possible that doctors do not find these discussions emotionally difficult, or chose not to talk about this difficulty if they did. The doctors spoke instead of disagreements they encountered with parents of disabled children as to a child's best interests, describing the parents as being difficult:

Dr 11

"Rationalising extreme views, especially intransigent religious doctrine"
and

Dr 17

When the family have unrealistic expectations – disabled children often have impaired physiology and are more unstable and often more difficult to get out of PICU successfully."

Other doctors, in contrast used language suggesting empathy towards a child and his or her parents, for example:

⁵⁹⁷ Chapter six, para 5.2, p.254

Dr 10

“To determine the needs of child and family and make sure that they make the best decision for themselves and their child”

and

Dr 16

“Getting it right given the different circumstances of each child, i.e. what is the best interests of the child and its family”

However, most doctors, while highlighting that dealing with parents was the most difficult aspect of their decision-making, tended to use more neutral language. For example:

Dr 2

“being in a position where you have a very different view of the child’s life and you feel continuing care is not the right decision for the child, however the parents are not at that point yet.”

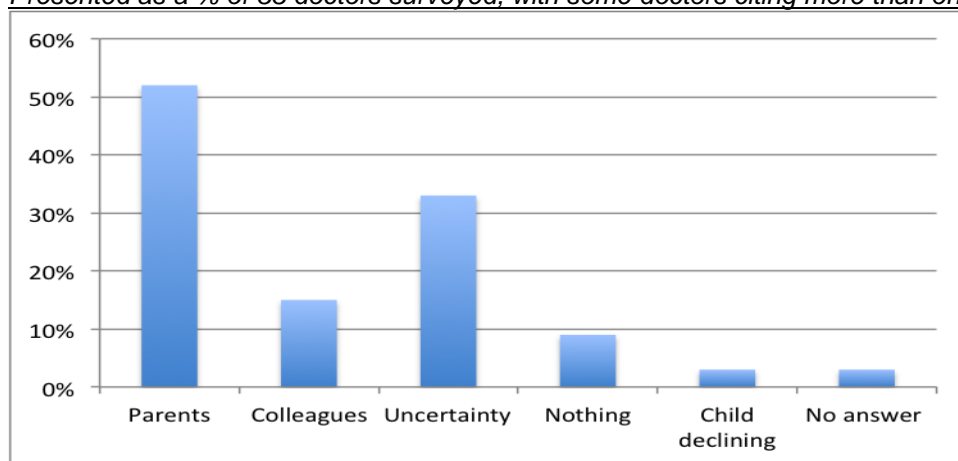
Two doctors, Drs 33 and 11, suggested disagreements with parents as to the child’s best interests arose from the parents’ religious beliefs. This is particularly significant in the context of the findings in this study of the possible impact of a doctor’s own religious beliefs presented in the next chapter.⁵⁹⁸

Whilst seventeen doctors (52%) cited what in broad terms can be described as communicating with parents, as the most or one of the most difficult aspect of difficult decision-making, there was a notable difference between the sub-specialties namely the PICU consultants, neurologists and the other doctors (‘Other Doctors’) as a group. Whilst seven PICU consultants (70%) cited communication with parents or another as the most difficult aspect of decision-making for disabled children, only two neurologists (22%) did. Eight Other Doctors (57%) also cited dealing with parents as being the most or one of the most difficult aspect of these decisions.

⁵⁹⁸ Chapter five, pp. 181-236

Other difficulties in decision-making were also highlighted. Disagreements with other health professionals was cited by five doctors (15%) - Drs 5, 11, 13, 18 and 20 - as among the most difficult aspects of these decisions. Two doctors (6%), Drs 32 and Dr.14 both cited the difficulty of gaining the child's perspective as one of the most difficult aspect of these decisions. Uncertainty also featured repeatedly in the doctors' answers, with eleven doctors (33%) citing uncertainty as to when or whether to withhold or withdraw treatment as amongst the most difficult aspects of the decision. Neurologists seemed to particularly cite uncertainty with four neurologists (44%) mentioning it, compared with just one PICU consultants (10%). However, three doctors (9%); (two neurologists and one PICU consultant) said they did not find any aspect of these decisions difficult. Dr 9 writing *"It all takes focus and the ability to listen carefully to parents and the child (if able to contribute)."* One doctor, Dr 6 cited the child 'declining,' as a difficult aspect of these decisions.

Figure 24: Factors doctors find most difficult when making difficult decisions for disabled children
Presented as a % of 33 doctors surveyed, with some doctors citing more than one factor.



6. Which factors do doctors consider when making decisions?

Having established what kind of decisions doctors found difficult when deciding for disabled children and what, in the doctors' views made those decisions particularly difficult, the doctors were then asked about *how* they made their

decisions. The aim of these questions was to ascertain what factors the doctors considered when deciding for disabled children and what weight the doctors put on those factors. These responses can then be compared with how doctors are guided to make their decisions by their professional bodies and the extent to which, going back to the Kennedy debate, doctors draw on clinical and non-clinical factors, as defined as the start of this chapter.

The first question the doctors were asked was: ‘*What are the main factors you consider when making these decisions?*’ Their responses classified as clinical or non-clinical factors are now presented.

6.1 Clinical Factors

It will be recalled that clinical factors in this thesis⁵⁹⁹ refers to biomedical observable and measurable factors within the unique expertise and competence of a medical doctor. They are distinguished from non-clinical factors such as a child’s quality of life.

Five doctors (15%) unambiguously stated they included clinical factors when deciding for a disabled child. For example:

Dr 1

“Likelihood of future disease recovery/deterioration/deterioration & related impact on need for future intensification of support”

Dr 13

“Previous response to acute therapy”

Dr 31

“chances of recovery to baseline, burden of therapies”

A further eleven doctors (33%) included factors that can be read as clinical factors, however the words used are ambiguous so could also be read to mean or include non-clinical factors, for example:

⁵⁹⁹ Chapter four, para 2, pp. 139-141

Dr 3

“what is medically achievable”

Dr 7

“Consensus of health care staff”

Dr 11

“Impact on the child”

Dr 11’s response is particularly vague.

What is perhaps striking about the doctors’ responses is how few of the doctors mention or use words that can be clearly understood to refer to clinical factors, namely the child’s prognosis (only four doctors (12%)) or diagnosis (one doctor (3%)). Only nineteen doctors (57%) mentioned the child’s current clinical condition. The variation as to the clinical factors doctors said they considered is also noteworthy. For example, Dr 6 considers the trajectory⁶⁰⁰ of a child’s illness; Dr 28 considers the invasiveness of the procedure and Dr.14 the likelihood of future disease. Clearly, it is possible that doctors do consider many more factors than they cited in response to this question, indeed, there is some suggestion in the doctors’ responses to later questions in the survey, that suggest they do. Moreover, although no doctor wrote about taking different factors into consideration for different children, it is also possible that this is what doctors do. The doctors did, however, seem to suggest that clinical factors are not, as perhaps might be expected, the factors upon which doctors put the greatest weight when making difficult decisions for disabled children. Rather non-clinical factors, those Kennedy argued doctors do not have the unique

⁶⁰⁰ Health professionals refer to these patterns as the trajectory of an illness. See for example: Steele, R, Siden, H, Cadell, S et al (2013), *Archdischild*, 99(8), <http://dx.doi.org/10.1136/archdischild-2013-305246> accessed 12 January 2018. Different life limiting conditions are associated with different patterns of illness. With some conditions, such as cancer the trajectory is usually fairly predictable. For example, doctors are usually able to predict fairly accurately the course of an illness for an individual based on their signs and symptoms. For other conditions, such as many life limiting neurological conditions, doctors say it is far more difficult to predict the trajectory of an illness. This is often because patients with the condition follow too many variations in their trajectory or sometimes because the conditions are comparatively rare and doctors do not have enough evidence from other cases to predict a trajectory.

competence to assess, seemed to dominate. The doctors' responses, however, suggested a lot of variation between doctors as to the factors the doctors consider and the weight the doctors put on those factors. This is explored in more detail in the next chapter.⁶⁰¹

6.2 Non-clinical factors

Non-clinical factors include a child's quality of life; how well a child interacts with friends and family, whether a child attends school and even whether a child is happy. Law and ethics, discussed later in chapters eight and nine⁶⁰² are also included as non-clinical factors. Non-clinical factors are particularly relevant to the Kennedy debate, being he argues, outside the unique competence or education and training of doctors. Moreover, while doctors' professional guidance guides them to include these wider issues, the key question is perhaps, how the doctors include these wider issues, whether they make a judgment of these factors themselves, or canvass the views of those with appropriate knowledge and/or expertise.

Seventeen doctors (54%) listed the child's family or the child as a factor they consider, without stating in their brief answers what it was about the child or family that they consider. Thirteen doctors (39%) cited the child's quality of life as a factor considered when deciding for a disabled child. One doctor (3%), Dr 15 expressly stated that he or she⁶⁰³ did not make a judgment as to a child's quality of life. Another doctor (Dr 2) said in answer to this question that a child's cognitive ability is a relevant factor, however, as will be seen in the next chapter,⁶⁰⁴ when asked expressly whether they considered a child's cognitive ability, eight doctors (24%) suggested they put considerable weight on a child's

⁶⁰¹ Chapter five, pp.181-236

⁶⁰² Chapter eight, pp. 323-346, chapter nine, pp.347-380

⁶⁰³ Dr.15's gender was not declared.

⁶⁰⁴ Chapter five, para 6.2, p.227

cognitive ability as a factor in their decisions. This is further support to the earlier contention that the doctors' answers to this question covers just some of the factors doctors consider when making best interest decisions. At best, perhaps the factors the doctors list in answer to this question are the ones which come first to the doctors' mind. In the next chapter the weight doctors put on different factors is explored in detail.

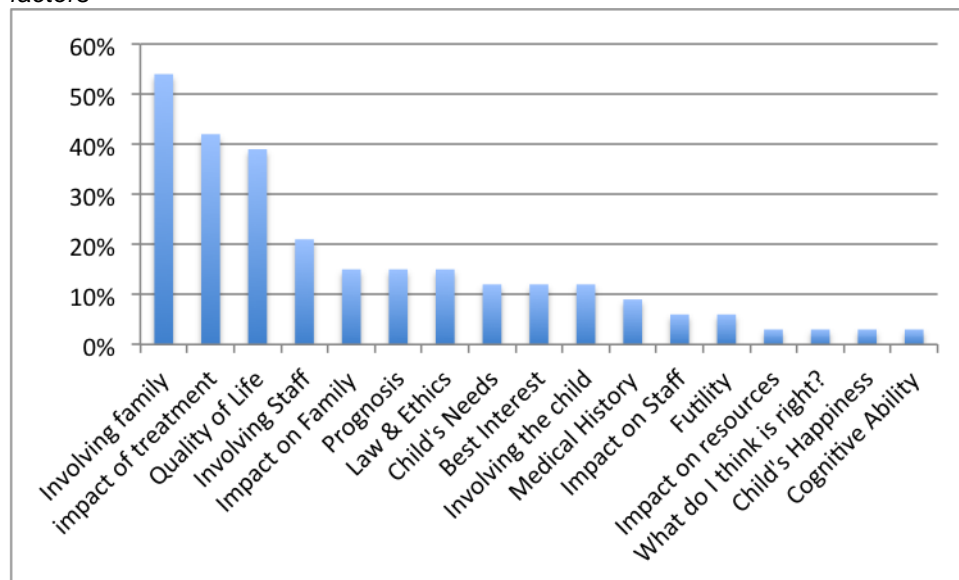
6.3 Law and ethics

Five doctors (15%) cited law and ethics in their survey responses - without prompting - as among the factors they consider when making difficult decisions for disabled children. Dr 8 said he considers "*The legal and ethical framework in which I work*"; Dr 16 listed "*ethical considerations, legal considerations*"; Dr 20 said he or she consider "*The law, as applicable*"; Dr 29 said he includes in his decision '*evidence, which may be of a law order*' and Dr 21 said he considered "*very occasionally the views of the court.*" These five doctors do not have any common professional or personal characteristics which distinguish them from the doctors who did not mention law, rights or ethics as a factor, other than three of the four, seem from their responses to later questions, to have had more in depth education and training in law and ethics than the other doctors, including for two of the doctors (Drs 8 & 16) received significant undergraduate education and training in law and ethics and undertook further post graduate studies in law and ethics. As a corollary, it is worthy of note that twenty-eight doctors (85%) did not unprompted mention law, rights or ethics as factors they consider when making difficult decisions for disabled children. In chapters eight and nine⁶⁰⁵ doctors' legal education and training is mapped against their responses across the survey and interviews, when the impact, if any, of law, rights and ethic on the doctors' decision-making is considered.

⁶⁰⁵ Chapter eight pp.323-346, chapter nine, pp.347-380

Figure 25: Factors doctors cite when asked 'What are the main factors you consider when making these decisions?'

Presented as a percentage of the doctors who cite each factor, with some doctors citing multiple factors



6.4 Best interests

Despite the professional guidance discussed earlier⁶⁰⁶ just four doctors (12%) expressly used the term '*best interests*' or '*interests of the child*' when listing factors that they consider. All the doctors who cited '*best interests*' were PICU consultants. Dr.25 who referred to "*interests of the child*" was an endocrinologist. Two of the PICU consultants worked in the same hospital, but otherwise there are no shared characteristics that seem to distinguish them from other participants. Although '*best interests*' were not expressly mentioned by the majority of doctors, a further nine doctors did cite factors which are important elements of the best interest test.⁶⁰⁷ For example, Drs 3; 31 and 32 all cited the balancing of benefits and burdens of treatment and Drs 1, 9; 8; 20, 27; and 21 all cited consulting widely with other health professionals and the child's parents. Dr 27 also included the child if possible, in the people to be consulted and Dr.1 included the child's siblings. This, however, left twenty

⁶⁰⁶ Chapter two, para 6, pp. 52-61 & chapter four, para 2, p.142

⁶⁰⁷ As the test is set out in cases such as *Re J (A Minor) (Wardship: Medical Treatment)* [1991]; 2 WLR 140

doctors (60.5%), who did not mention best interests or cite factors that very obviously could be read as a proxy for best interests, in response to this question. As can be seen in the next chapter, when analysing what the doctors said about prognosis, fertility, quality of life and a child's cognitive ability, more detailed consideration is given to whether the doctors do use any proxies for 'best interests' which might help explain the limited express references to best interests in the doctors' survey responses.

7. Further Analysis

Having in this chapter, explained who the participants are in this study; identified which decisions they find difficult; what makes these decisions particularly difficult; and in broad terms what factors the doctors consider, in the next chapter, chapter five, the weight put on key factors by the doctors is considered in detail.

In chapter six, the final chapter of part two, this thesis then turns to explore what the doctors who were interviewed, said about the part played by uncertainty and disagreement in their difficult decisions.

Part three of this thesis is concerned with a detailed exploration of the part played by law, if any, in doctors' best interests decisions. As previously explained, it starts with an explanation of legal consciousness theory, the theoretical framework used to explore the part played by law in the doctors' decisions. It then moves on in chapter eight to explore what can be learnt about the role of law from the doctors' survey responses and then in chapter nine to what can be learnt about the role law from the doctors' interviews. Part three and this thesis concludes, with chapter ten where conclusions are drawn and recommendations made.

Chapter Five

Prognosis, Futility, Quality of Life and Cognitive Ability

1. Introduction

This chapter expands on the last, by exploring in more depth what the doctors say about four key factors used in difficult decisions for disabled children, namely, prognosis, futility, quality of life and the child's cognitive ability. These four factors are chosen both because they were identified by the consultant paediatricians who advised on the survey questions, as being of particular interest in difficult decisions for disabled children and because the survey participants' responses seem to support this view. The survey responses, as shall be seen, suggest a lack of consensus amongst paediatricians, not just about what each factor actually addresses, but also as to which factors should be used. The three paediatricians who piloted the survey, as was discussed in chapter three,⁶⁰⁸ cautioned that some factors were so controversial that doctors may be wary of completing a survey that probed the doctors about them. They saw futility and quality of life as being particularly controversial and therefore sensitive.

With this in mind, a key aim when drafting the survey was to reach a balance between encouraging open reflection by the doctors about their decision-making, while not probing so deeply into sensitive areas that doctors were deterred from responding. However, while not wanting to alienate doctors, the controversial nature of these factors made it important to seek participants' views on them. It made it important to explore how widely concerns about their use are shared; important to ascertain the extent to which they are used in difficult decisions for disabled children; the weight put on them; and the extent to which there is consensus among paediatricians as to how best interest

⁶⁰⁸ Chapter three, para 4, p.139

decisions for disabled children are and should be made. However, avoiding alienating potential participants was also important so that as wide a range of paediatricians' views as possible could be canvassed. For this reason, a compromise position was adopted with more questions asked in the survey about less controversial factors such as prognosis and fewer questions about the more controversial factors such as futility and quality of life. More data was therefore sought in relation to some factors than others and this is reflected in the balance of this chapter.

2. Analysing doctors' responses

All four factors are analysed in the context of five professional and personal characteristics; namely the doctors' sub-specialism; gender; personal experience of disability; duration of practice and religious faith. This was done to assess whether there is any suggestion in the data that doctors who share particular characteristics think or act differently from doctors who do not share those characteristics. These five characteristics are used, first, because they seem to be most pertinent and also because each of these characteristics is shared by a number of doctors in the pool making comparisons of groups of doctors (as opposed to individual doctors) possible.

When analysing the weight doctors placed on each factor, the doctors' responses were categorised into four groups. These were answers:

- i. suggesting the doctor uses and puts a lot of weight on that factor;
- ii. suggesting that the doctor showed unease at the factor being used;
- iii. suggesting a middle ground between (i) and (ii) for example, the doctor uses the factor but with some reservations or uses it in particular circumstances but not others; and
- iv. the doctor either did not answer the question or gave an unclear answer.

To enable comparison between the different paediatric sub-specialties, the doctors are divided into three groups, namely PICU consultants, neurologists

and 'Other Doctors'. With ten PICU consultants and nine neurologists responding to the survey, comparison between these two groups is particularly instructive. The comparison is a particularly interesting one, as doctors from these two sub-specialties are likely to have very different experiences of the children and their families.

Neurologists are among the sub-specialisms more likely to have long-term involvement in a child's healthcare. Moreover, most children with whom neurologists work will have, to a greater or lesser extent, some level of impairment and many will have severe physical and/or cognitive impairment, making neurologists medical experts on child disability.

In contrast, a PICU consultant will see a child when he or she is critically ill and possibly sedated. A PICU consultant is very unlikely to see a child patient when he or she is well. Although a small number of children may be admitted to PICU more than once; a child would not necessarily be under the care of the same PICU consultant for each admission. It is more usual for a child to attend PICU only once, if at all. A PICU consultant is unlikely to be involved in the multi-disciplinary meetings routinely held for disabled children, unless a meeting happens to fall at a time whilst the child is in PICU, so is likely to have less background knowledge about a child than a neurology consultant. A PICU consultant is unlikely to have a long-term relationship with a child or his or her family, or have been involved in discussions concerning non-medical aspects of a child's life. A PICU consultant will be a medical expert on child critical illness. Neurologists and PICU consultants who responded to this survey will therefore be coming to the questions with very different professional experience of disabled children and their families.

The 'Other Doctors' group is made up of the remaining 14 doctors who responded to the survey in this study. As was seen in the last chapter, they come from a range of paediatric sub-specialties. They are grouped together as there are too few doctors from any single sub-specialty to enable a meaningful

comparison of that specialty's training, expertise or culture on decision-making. The Other Doctors will have a range of experiences of disabled children and their families. Some, such as the neonatologists are, similarly to PICU consultants, more likely to see the children only when they are acutely unwell. Others such as the palliative care consultant and oncologist are, like the neurologists, more likely to have long term relationships with the children and their families, and be involved in multi-disciplinary discussions and non-medical aspects of the child's life.

What the doctors wrote about each of the four factors in now presented and analysed in turn.

3. Prognosis

3.1 Defining prognosis

Prognosis can be defined as:-

'a forecast of the probable course and outcome of an attack of disease and the prospect of recovery as indicated by the nature of the disease and the symptoms of the case.'⁶⁰⁹

Arguably a child's prognosis, being an indication of the disease trajectory and likelihood of recovery, would seem to be the most important factor a doctor considers when deciding whether to withhold or withdraw treatment. A child, it is presumed, will be treated if there is a good prospect of recovery, but may not if the prospect of recovery is poor and the burden of any treatment is seen to outweigh the benefit. Prognosis as defined above, can be viewed as a clinical factor, the scientifically measurable progression of the disease.

The doctors' responses gave some indication of how they conceptualise 'prognosis' and the extent to which there is consensus amongst doctors as to its relevance to best interest decisions. The doctors started by explaining the

⁶⁰⁹ Source: www.medical-dictionary.thefreedictionary.com/prognosis; last accessed 25 March 2016

weight they put on prognosis as a factor in their decisions, by answering the question ‘*What part does a child’s medical prognosis play?*’ They then explained what factors they include when making a prognosis.

3.2 Weight attributed to prognosis

The doctors were divided as to the weight that should be put on a disabled child’s prognosis. Their responses were assessed using the four categories of a lot of weight, unease, middle ground or no or unclear answer, outlined earlier.⁶¹⁰ Some doctors saw it as a key factor. For example:

Dr 15 (Other) “*large part*”

Dr 23 (neurologist) “*A huge part*”

Dr.28 (PICU) “*Fundamental*”

Other doctors expressed more reservations. For example:

Dr 1 (neurologist)

“In theory a major part – in connect with the concept of futility- although in practice uncertainty over prognosis means role is less dominant.”

Dr 27 (Other) “*hugely but sometimes hard to judge.*”

For some doctors, prognosis was part of a balance of several factors. For example:

Dr 12 (PICU)

“Weighed in balance with other acute clinical factors. Not overriding, consideration if the other conditions are readily remediable.”

Dr 24 (neurologist)

“It is always a consideration but not the only one. For instance, even when death is expected relatively soon, there may be a lot of merit in a procedure which will enhance the child’s remaining quality of life.”

⁶¹⁰ Chapter five, para 2, p. 182

Overall twenty doctors (60.5%) gave answers suggesting prognosis was either the most important factor or one of the most important, in their best interest decisions. Three doctors (9%) expressed unease at its use and eight doctors (24%) expressed mixed feelings. The remaining doctors either did not answer the question or gave answers where the meaning was unclear.

3.3 How is prognosis assessed?

To further evaluate the doctors' understanding of prognosis and whether they all meant the same thing, doctors were also asked what factors they consider when making a prognosis for a disabled child. The trajectory of illness was mentioned by eight doctors (24%), three neurologists (Drs 7, 19 & 24); two PICU consultants (Drs.16 & 33) and three Other Doctors; (Drs.8, 26 and 14). Two doctors (6%), (Drs 11 & 15), both PICU consultants, commented that they consider the same factors for both a disabled and a non-disabled child, but did not indicate what these were. Other factors listed by the doctors included "severity" (Dr.1 Neurologist) '*pain and discomfort*' (Dr.20, Other); "*current clinical knowledge about the condition*" (Dr.26, Other) and "*parental aspiration*" (Dr.31, PICU). It is unclear what Dr 31 meant by this, in this context.

3.4 How do the sub-specialties compare on prognosis?

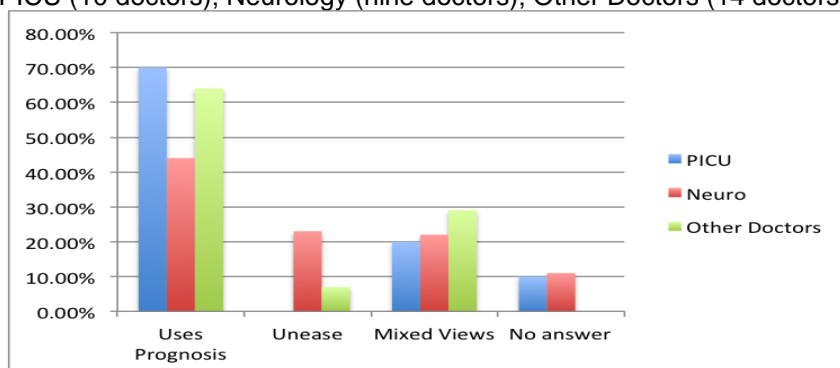
When the doctors' answers are compared by sub-specialty using the methodology outlined earlier, as Figure 26 illustrates, the responses seem to suggest that PICU consultants were more likely to use prognosis as a factor in their decisions than neurologists. Seven PICU consultants (70%) expressed enthusiasm for its use and none of the PICU consultants expressed unease. In contrast four neurologists (44%) expressed unreserved enthusiasm for its use and two (22%) stated they did not think prognosis should be used as a factor in these decisions. The Other Doctors were also largely positive about its use, with nine Other Doctors (64%) endorsing its use and only one (7%) expressing concerns. When it came to doctors who took a middle ground position; seeing some positives but also recognising that at least in some situations there could be problems relying on prognosis, there was more parity between the sub-

specialties, with two PICU consultants (20%), two neurologists (22%) and four (29%) of the Other Doctors adopting this position in their survey answers.

Figure 26: Use of prognosis by sub-specialties

Presented as a percentage of each sub-specialty

PICU (10 doctors); Neurology (nine doctors); Other Doctors (14 doctors)



Many of the doctors' answers seem to suggest the doctors were answering a different question from the one asked: namely what do they consider once they have a prognosis? However, based on the responses the doctors gave, the answers were analysed to examine the extent to which doctors cited clinical and non-clinical factors, as defined in the last chapter.⁶¹¹

The doctors' responses suggest that the neurologists were potentially more inclined to define prognosis based on clinical factors, compared with PICU consultants who seemed from their responses more likely to include non-clinical factors. For example, three PICU consultants (30%) cited '*family expectations*' (Dr.15); '*parental aspirations*' (Dr.31) and '*how much time spent at home, what do the parents think about quality of life*' (Dr.17). These are arguably factors one would expect to see in a best interest evaluation, including wider-ranging welfare factors, rather than an assessment of a child's prognosis. It is possible that these doctors were using prognosis as a proxy for best interests. It is also, of course, possible that the doctors misunderstood the question. Five PICU consultants (50%) listed just non-clinical factors compared with no neurologists and five Other Doctors (36%). In contrast, two PICU consultants (20%) listed

⁶¹¹ Chapter four, para 2, pp. 139-142

just clinical factors as those they consider when making a prognosis compared with four neurologists (44%) and six Other Doctors (43%). No neurologists gave a mixed answer, so no neurologists suggested he or she used non-clinical factors when making a prognosis. One PICU consultant (10%) gave a mixed answer suggesting they used clinical and non-clinical factors and three Other Doctors (21%) did the same. Five neurologists (56%) and two PICU consultants (20%) did not answer this question. This included the doctors who had indicated earlier in the survey that they did not use prognosis when deciding for disabled children.

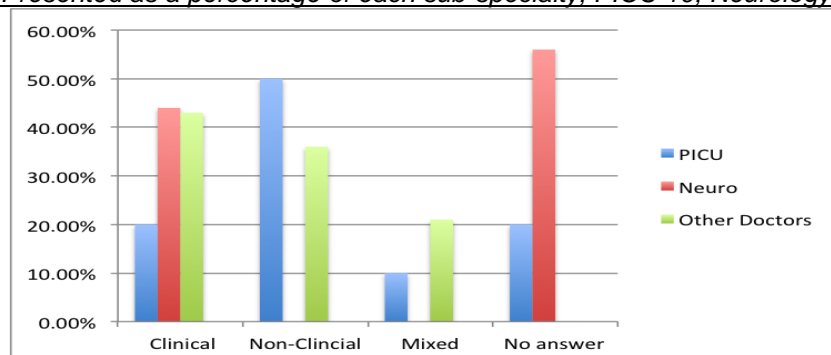
In summary, the doctors' responses to this question suggest that doctors mean different things by the term prognosis. For neurologists, it seems to be a clinical determination and for PICU consultants and Other Doctors it seems to encompass non-clinical factors, those factors the Kennedy Debate suggested doctors should not be using. Moreover, as was seen earlier,⁶¹² PICU consultants, it is argued, are less likely to be familiar with the non-clinical aspects of a disabled child's life, than a neurologist. It seems that particularly for PICU consultants and Other Doctors, prognosis was possibly being used as a proxy for best interests. A key question and a major theme of the doctors' interview discussions, considered in the next chapter,⁶¹³ is how the non-clinical aspects are assessed, particularly by PICU consultants? We shall also see that doctors discussed at some length disagreements between doctors, what is not clear here, is the extent to which these disagreements arise because different doctors have different understandings of key factors, such as prognosis, when deciding for a severely disabled child.

⁶¹² Chapter five, para 2, p. 182

⁶¹³ Chapter six, para 7, p.261-282

Figure 27: Use of clinical and non-clinical factors when assessing prognosis

Presented as a percentage of each sub-specialty; PICU 10; Neurology 9; Other Doctors 14

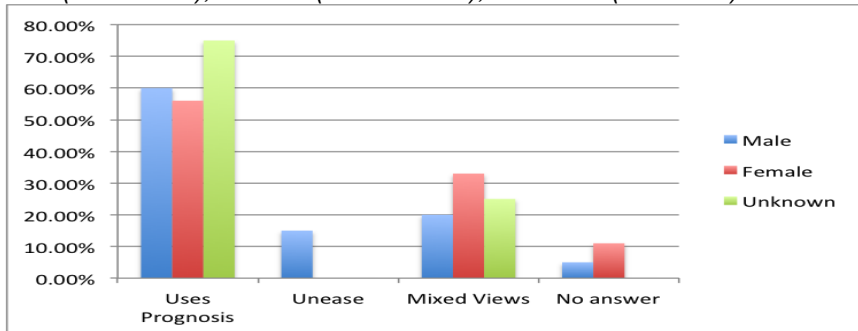


3.5 How do male and female doctors compare on prognosis?

The responses given by male and female doctors were also compared using the same methodology to identify any differences in the responses given. As was seen in the last chapter, twenty doctors (60.5%) indicated they were male and nine (27%) that they were female doctors. Four doctors (12%) did not reveal their gender.

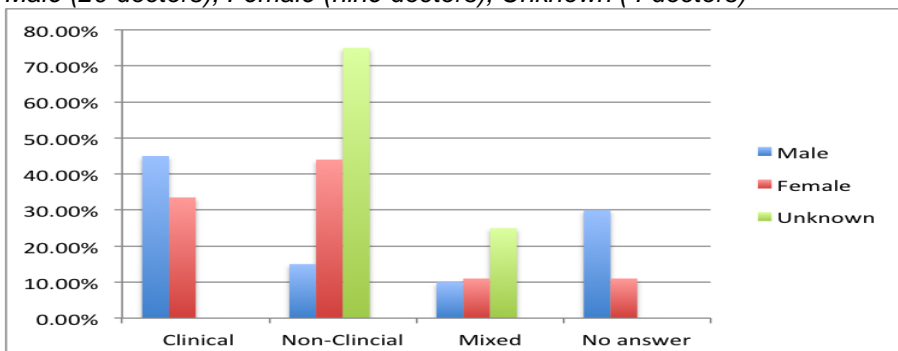
No great differences between the genders can be seen in attitudes towards prognosis as a factor; with twelve male doctors (60%) and five female doctors (56%) giving answers suggesting they are enthusiastic about its use. It is however, noteworthy that while only three doctors expressed significant unease at the use of prognosis in these decisions, they were all male doctors. The pool of male doctors was more than twice that of the female pool. With a larger pool of female doctors, it is possible that one or more female doctor could have also expressed unease. Three female doctors (33%) expressed a mixed view, seeing both positives and negatives in its use, as did four male doctors (20%) but again, the small number of female doctors means that drawing firm conclusions about gender differences is not possible.

Figure 28: Use of prognosis and gender
 Presented as a percentage of each gender
 Male (20 doctors); Female (nine doctors); Unknown (4 doctors)



The doctors' responses were also examined to consider whether male and female doctors show any differences in their use of clinical or non-clinical factors when making a prognosis. Nine male doctors (45%) used clinical factors compared with three female doctors (33%). Three male doctors (15%) used non-clinical factors compared with four female doctors (44%). This suggests the male doctors were more inclined to use clinical factors and female doctors, non-clinical factors to define prognosis. Again however, the numbers are too small to come to reliable conclusions.

Figure 29: Doctors' use of clinical and non-clinical factors when assessing prognosis
 Presented as a percentage of each gender
 Male (20 doctors); Female (nine doctors); Unknown (4 doctors)



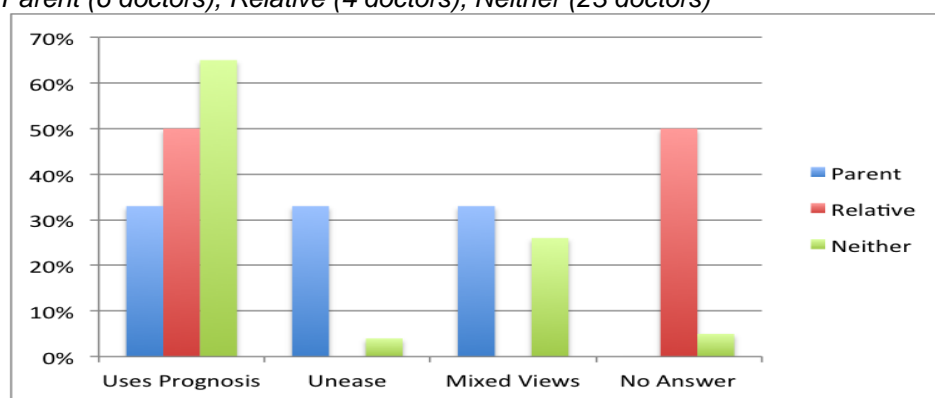
Having considered the impact, if any, of a doctor's gender on the doctor's use of prognosis as a factor when deciding for disabled children, consideration is now given to the impact, if any, of a doctor's personal experience of disability.

3.6 How do doctors with different personal experience of disability compare in their approaches to prognosis?

The responses given by doctors classified by their personal experience of disability were compared using the methodology outlined above, to ascertain whether there were any differences in the responses given. The doctors were classified into three groups, namely, (i) doctors who indicated they were a parent of a disabled child, ('parent doctors'); (ii) doctors who had indicated they had a close disabled relative, other than their child, ('relative doctors') and (iii) doctors who had no personal experience of disability, ('no-experience doctors').

As figure 30 illustrates, fifteen no-experience doctors (65%) indicated they put considerable weight on prognosis as a factor; compared with two parent doctors (33%) and two relative doctors (50%). Parent doctors seemed more likely than no-experience doctors or relative doctors to object to the use of prognosis, with two parent doctors (33%) indicating this, compared with one no-experience doctor (4%) and none of the relative doctors. None of the relative doctors took a mixed approach to prognosis, but two parent doctors (33%) and six no-experience doctors (26%) took this approach. The remaining doctors did not answer the question.

*Figure 30: Use of prognosis and personal experience of disability
Presented as a percentage of doctors by personal experience of disability
Parent (6 doctors); Relative (4 doctors); Neither (23 doctors)*

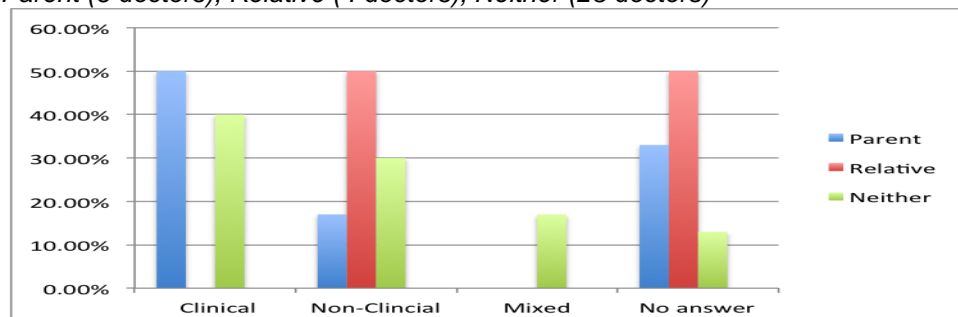


The doctors' responses were also analysed to consider any differences in the extent to which the three groups of doctors included clinical or non-clinical factors when deciding a prognosis. As can be seen from figure 31, while three parent doctors (50%) and nine no-experience doctors (39%) used clinical factors to make a prognosis; none of the relative doctors said they did. In contrast two relative doctors (50%) reported using non-clinical factors, while only one parent doctor (17%) did so. This compares with seven no-experience doctors (30%) reporting using non-clinical factors. It is also noteworthy that the no-experience doctors who answered this question seemed to express strong views one way or the other, with none giving a mixed answer. It should, however, also be noted that two parent doctors (33%) and two relative doctors (50%) did not answer the question or gave an unclear answer regarding clinical or non-clinical factors. These findings seem to suggest that doctors who have personal experience of disability may approach difficult decisions for disabled children differently from doctors who do not. Moreover, the nature of that personal experience seems to potentially make a difference, with parent doctors seeming to answer questions differently from relative doctors. It is perhaps noteworthy, that neurologists (the doctors as a group who have the most day-to-day professional experience of disabled children's lives) and parent doctors, (the doctors who have the most personal experience of disabled children's lives), seem to both as sub-groups, be less inclined to put weight on prognosis, but when they do, both groups tend to define prognosis as a clinical factor. This seems to echo the finding in chapter four⁶¹⁴ of neurologists, when compared with PICU consultants, disagreeing less often with parents.

⁶¹⁴ Chapter four, para 5.4, pp.172

Figure 31: Use of clinical and non-clinical factors when assessing prognosis by the doctor's personal experience of disability

*Presented as a percentage of doctors by personal experience of disability
Parent (6 doctors); Relative (4 doctors); Neither (23 doctors)*



3.7 How do different generations of doctors compare in their approaches to prognosis?

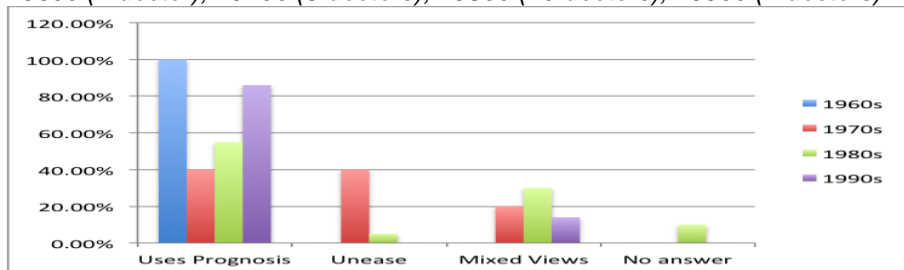
Consideration was also given as to whether doctors who qualified in different decades approached prognosis as a factor the same or differently. If there were differences this could be due to doctors changing their approaches as they gained more experience or it could reflect differences in cultures, values and training from different eras. The responses from doctors who qualified during the 1960s; 1970s; 1980s and 1990s were compared using the same methodology as for the other factors. Only one doctor who qualified in the 1960s responded to the survey. His responses are included in the illustrative charts in this chapter for completeness, but not in any discussion, as he represents just a single viewpoint from that decade. As was seen in the chapter four,⁶¹⁵ one doctor (3%) qualified in the 1960s, ('1960s qualifiers'); five (15%) in the 1970s, ('1970s qualifiers'); twenty (60.5%) in the 1980s, ('1980s qualifiers') and seven doctors (21%) qualified in the 1990s ('1990s qualifiers').

The doctors' responses do seem to indicate a possible trend, with doctors seeming to put less weight on prognosis the longer they are in practice. Two 1970s qualifiers (40%) indicated they put considerable weight on prognosis and the same number of 1970s qualifiers indicated unease at its use. However, this compares with six 1990s qualifiers (86%) being positive about prognosis as a

⁶¹⁵ Chapter four, para 4.5, pp. 157-158

factor. None of the 1990s qualifiers expressed unease at its use. The responses from 1980s qualifiers showed positions between these two, with eleven (55%) indicating positive views of the use of prognosis as a factor and one (5%) expressing unease at its use.

Figure 32: Use of prognosis and duration of practice
Presented as a percentage of doctors qualifying in each decade
1960s (1 doctor); 1970s (5 doctors); 1980s (20 doctors); 1990s (7 doctors)



When the data is further examined to explore whether duration of practice seemed to influence whether doctors perceived prognosis as clinical or non-clinical, there also seemed to be differences reflecting the decades in which doctors qualified. The doctors' responses suggest that the longer a doctor has been qualified the more likely a doctor is to use clinical factors when making a prognosis and the less likely a doctor is to use non-clinical factors. Three 1970s qualifiers (60%) listed clinical factors; this reduced (in percentage terms) to seven 1980s qualifiers (35%) and two 1990s qualifiers (29%). In contrast while three 1990s qualifiers (43%) reported using non-clinical factors; this reduced to six 1980s qualifiers (30%) and one 1970s qualifier (20%). This seems to suggest that doctors qualifying in the era of the Kennedy Debate were less likely to use non-clinical factors than more recently qualified doctors.

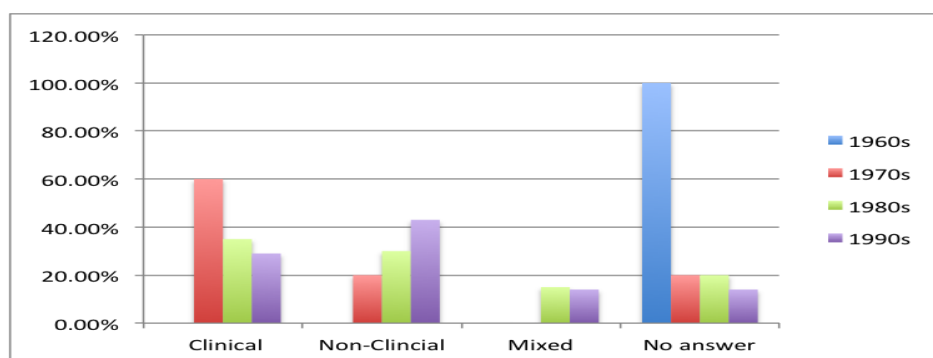
These findings perhaps also say something about the impact or otherwise of the hidden curriculum highlighted in chapter three.⁶¹⁶ More recently qualified doctors are trained and educated by doctors who qualified in earlier decades

⁶¹⁶Chapter three, para 2.2, pp.100-101

both formally and Hafferty and Franks⁶¹⁷ suggested through the hidden curriculum. However, these results tend to suggest that either doctors train juniors to make decisions differently from how they say they make them themselves, or the more recently qualified doctors are influenced by something other than their senior colleagues. Doctors who were later interviewed addressed the difference in approach of doctors from different generations to these decisions, as is seen in chapter six.⁶¹⁸

Figure 33: Use of clinical and non-clinical factors when assessing prognosis by the doctor's decade of qualification

Presented as percentage of doctors from each decade: 1960s (1 doctor); 1970s (5 doctors); 1980s (20 doctors); 1990s (7 doctors)



3.8 How do doctors with and without a religious faith compare in their approaches to prognosis?

The doctors' responses were also examined using the same methodology to explore whether there was any suggestion in the data that doctors who practice a religious faith approach prognosis differently from doctors who do not have a faith.

As was seen in chapter four,⁶¹⁹ larger studies have found that a doctor's religious faith can influence his or her decision-making for patients. As was

⁶¹⁷ Hafferty, F, Franks R, (1994) The Hidden Curriculum, Ethic Teaching and the Structure of Medical Education, *Academic Medicine*, Vol. 69(11), pp.861-871

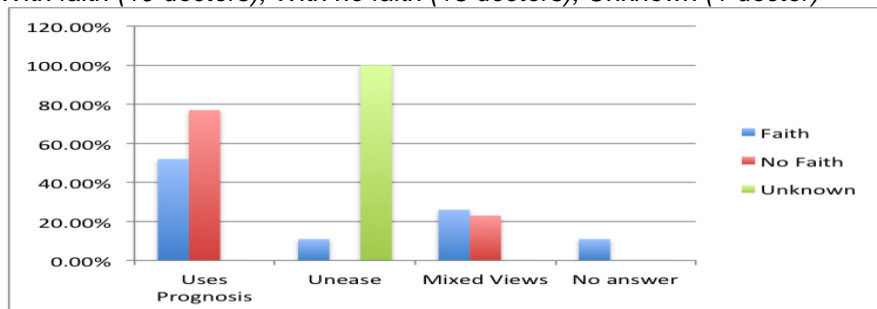
⁶¹⁸ Chapter six, para.7.1.3, pp. 267-268

⁶¹⁹ Chapter four, para 3, p.146

seen in the last chapter⁶²⁰ nineteen doctors (57%) in this study describe themselves as belonging to a particular religion or faith, predominantly Christianity. The answers from doctors who said they followed a faith ('religious doctors') were compared with those who said they did not ('non-religious doctors'). One religious doctors (5%) reported putting weight on prognosis, compared with ten non-religious doctors (78%). Three religious doctors (11%) reported unease at the use of prognosis, none of the non-religious doctors did so. Similar percentages of religious doctors and non-religious doctors had mixed views about prognosis, with five religious doctors (26%) suggesting this and three non-religious doctors (23%).

Figure 34: Use of prognosis and religious faith

*Presented as a percentage of doctors with and without religious faith
With faith (19 doctors); With no faith (13 doctors); Unknown (1 doctor)*



The doctors' responses were also examined to consider whether religious doctors and non-religious doctors showed any differences in their use of clinical or non-clinical factors when making a prognosis. Ten religious doctors (52%) used clinical factors compared with two non-religious doctors (15%). Three religious doctors (11%) used non-clinical factors compared with seven non-religious doctors (54%). These findings seem to support earlier studies⁶²¹ and confirm that a doctor's faith may impact his or her decisions for disabled children.

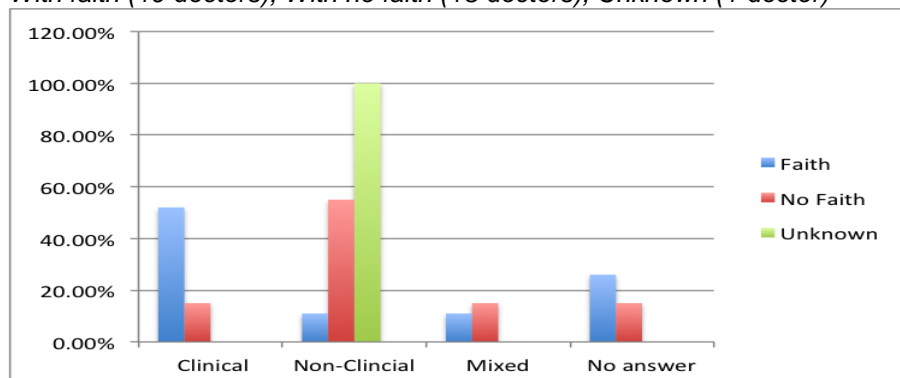
⁶²⁰ Chapter four, para 4.10, p.166

⁶²¹ For example, Cuttini, M, Nadai, M, Kaminski, M, Hansen, G, de Leeuw, Lenoir, S, Persson, J, et al (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries, *The Lancet* 355.9221: 2112-2118

Figure 35: Use of clinical and non-clinical factors when assessing prognosis by the doctor's religious faith

Presented as a percentage of doctors with and without religious faith

With faith (19 doctors); With no faith (13 doctors); Unknown (1 doctor)



To summarise, what the data suggests about the use of prognosis: a doctor's professional and personal characteristics do seem to potentially impact on how a doctor uses prognosis when making difficult decisions for disabled children and how a doctor defines prognosis. PICU consultants; Other Doctors; non-religious doctors; 1990s qualifiers and no-experience doctors, seem to put more weight on prognosis than doctors who do not share these characteristics. For all doctors who use prognosis, neurologists; male doctors, religious doctors; 1970s and parent doctors seem more likely to include clinical factors within their definitions of prognosis. PICU consultants; female doctors; non-religious doctor; 1990s and no-experience doctors, seem more likely to include non-clinical factors in their definition of prognosis. This supports Kennedy's contention that doctors use non-clinical factors. However, it also perhaps suggests that these doctors are using prognosis much more as a proxy for best interests, drawing on wider welfare factors. The questions addressed in chapter six,⁶²² (while addressing research question two),⁶²³ is how the doctors make these non-clinical assessments and whether, as Kennedy argues, in doing so doctors are going beyond their knowledge and expertise.

⁶²² Chapter six, para 4.2, pp. 246-251

⁶²³ 'What factors do UK paediatricians take into consideration when making difficult decisions for disabled children and what weight do they put on those factors?'

Consideration is now given to comparing what the same sub-groups of doctors wrote in their surveys about their use or otherwise of futility as a factor in their difficult decisions for disabled children.

4. **Futility**

4.1 Defining Futility

Criticism of the use of futility as a factor in doctors' decision making for patients generally is not hard to find.⁶²⁴ Laurie et al describe futility as 'fraught with difficulties and contradictions'.⁶²⁵ As was seen at the start of this chapter,⁶²⁶ the three paediatricians who piloted the study survey identified futility as being a particularly controversial factor in difficult decisions for disabled children, not least because of a lack of consensus as to its meaning. This concern is shared by others. For example, Jecker and Perlman⁶²⁷ identified four different ways in which medical treatment can be deemed futile, namely:

"(1) is useless or ineffective; (2) fails to offer a minimum quality of life or a modicum of medical benefit; (3) cannot possibly achieve the patient's goals; or (4) does not offer a reasonable chance of survival."

It can be seen that even if agreement were reached as to which definition is the optimum one, the meaning of each is open to further debate. For example, what is a 'minimum quality of life' or a 'reasonable chance of survival'? It can be seen why the paediatricians were cautious about its use.

⁶²⁴ see for example: Gampel, E (2006) Does Professional Autonomy Protect Medical Futility Judgments? *Bioethics*, Vol. 20, Number 2, pp.92-104; Lantos, JD, Singer, PA, Walker, RM (1989) The Illusion of Futility in Clinical Practice, *AM J Med* 87:81-84; & Ardagh, M (2000) Futility has no utility in resuscitation medicine, *Journal of medical ethics*, 26.5 396-399

⁶²⁵ Laurie GT, Harmon HE, Porter G '(2016) *Medical Futility*,' Chapter 15 in Laurie GT, Harmon S, Porter G in Mason & McCall Smith's *Law & Medical Ethics* (10th edn), Oxford University Press, p. 516, Para 15.06

⁶²⁶ Chapter five, para 1, p. 181

⁶²⁷ Jecker, NS, Pearlman, RA (1992) Medical Futility: Who Decides?, *Arch Intern Med*. 152(6), pp 1140-1144, at p.1140

A distinction is often made between quantitative futility and qualitative futility. Quantitative futility is where a treatment is seen as having little likelihood of benefit to the patient in clinical terms, namely the procedure or medication is unlikely to work for the patient. In contrast, qualitative futility is where the procedure or medication will work, but it is viewed as doing little to improve the quality of the patient's life, so is futile.⁶²⁸ An example might be that ventilating a patient will keep the patient alive, but the quality of the patient's life is considered to be so poor that the patient's life is not perceived to be worth saving. The case of *Re J* [1991]⁶²⁹ discussed in chapter two,⁶³⁰ was an early example of the consideration of qualitative futility by the courts in the context of a disabled infant's best interests, concerning as it did, the question of whether J's life was one that *should* be saved, rather than one that *could* be saved. In the context of the Kennedy debate, quantitative futility can perhaps be framed as an assessment within the legitimate expertise of a doctor. It involves questions such as whether a medication or procedure will scientifically work. In contrast, qualitative futility; questions such as what quality of life is worth preserving, are as Kennedy argued, perhaps beyond the legitimate and unique training, expertise and experience of a doctor. The link between qualitative futility and quality of life assessments is an important one. The discussion later in this chapter in relation to the doctors' quality of life assessments is therefore also relevant in relation to qualitative futility assessments.

The doctors' responses in this study showed a variety of viewpoints as to whether futility should be used in difficult decisions for disabled children and the weight that should be put on it.

⁶²⁸Foxall, F (2009) 'Ethical Issues', Chapter 4, in Jevon P (ed) *Care of the Dying and Deceased Patient: A Practical Guide for Nurses*, John Wiley & Sons, p.89

⁶²⁹ *Re J (A Minor) (Wardship: Medical Treatment* [1991] [1991] Fam. 33; [1991] 2 W.L.R. 140; per Lord Donaldson

⁶³⁰ Chapter two, para 3, pp. 39-43

4.2 Weight attributed to futility

The doctors' answers to the one question asked about futility: 'What part does futility play in difficult decisions for disabled children?' were mostly very brief. They ranged from doctors who saw it as an important factor in their decisions, for example: Dr 1 (neurologist) who answered "*significant*"; Drs 18 (PICU) and Dr 19 (neurologist), both answered "*Large part*"; Dr.25 (Other) '*Considerable*' and Dr 33 (PICU) "*Major*", to Dr 30 (neurologist) who answered "*None in my practice.*"

Doctors talked of the difficulty in obtaining consensus as to whether treatment was futile. For example, Dr12 (PICU) said, "*Difficulty is often reached in getting all parties agreement that treatment is futile.*" Dr 24 (neurologist) also expressed difficulties with the term and saw it as the source of conflict between both the healthcare team and the child's family, stating:

"Can make the process harder as this is often where professionals and family do not see eye to eye, with professionals generally having a stronger sense of futility than the family who are desperate to 'try anything'. This has the potential to led to a breakdown in the professional relationship, which has to be avoided. It can also result in conflict between members of the healthcare team."

Dr 20 (Other) also expressed concerns at how some doctors use the term stating

"futility is not a very helpful term, it's kind of shorthand for the doctor's opinion that the child's life isn't worth living. When used it needs to be fleshed out a bit."

What is unclear from the brief survey answers is how doctors are understanding the term futility and whether they are referring to quantitative or qualitative futility. It is possible that doctors who express opposing views are using the term differently.

4.3 How is futility assessed?

For the reasons discussed earlier⁶³¹ the doctors were not asked, as they were for prognosis, what factors they included when considering futility. However, some doctors did comment further on futility in their responses. For example, Dr 2 (PICU) described the assessment of futility as a “*judgment and not a clear black and white science, it is difficult.*” This was a view echoed by other doctors. For example, Dr 16 (PICU) “*in real life futility is often relative and it is a balance between medical opinion.*”

4.4 How do the sub-specialties compare on futility?

When the doctors' answers are compared by sub-specialty using the methodology outlined earlier, there is some indication of perhaps a difference in attitudes between PICU consultants and neurologists. PICU consultants seem perhaps more inclined to include futility as a factor in their decision-making. Whereas only one neurologist (11%) wrote positively about futility as a factor; five PICU consultants (50%) were positive about its use. However, the picture was far from clear-cut as four PICU consultants (40%) and four neurologists (44%) expressed concerns about its use. Indeed, the data seems to suggest that PICU consultants and neurologists have clearer opinions on futility than Other Doctors. No PICU consultant indicated a middle ground position and only two neurologists (22%) doing so. In contrast, the Other Doctors who expressed a view were equally spread across the viewpoints with four (29%) favouring the use of futility in difficult decisions; four (29%) indicating unease at its use and four (29%) taking a middle ground stance. It is the diversity of views among the doctors, (something the pilot consultants suggested would be found) which is perhaps the most striking here. PICU consultants seemed to have less reservations about its use when deciding for disabled children compared in particular to neurologists.

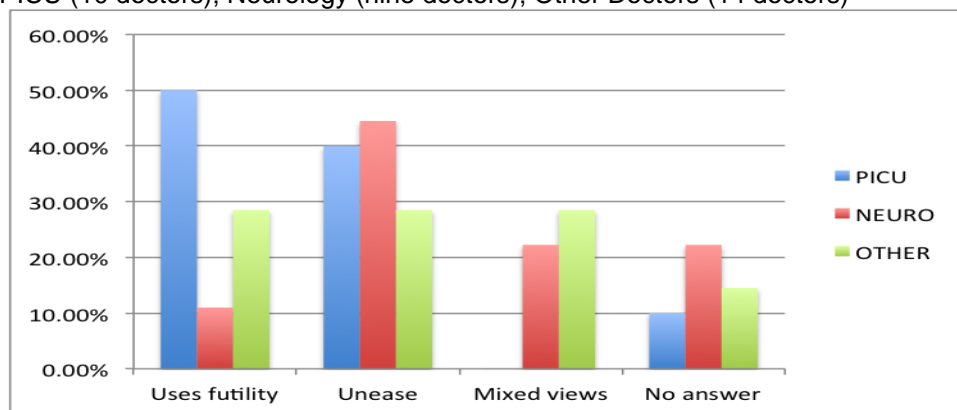
⁶³¹ Chapter five, para 1, p.181

The doctors were not asked which factors they considered when assessing futility, so no analysis of the use of clinical and non-clinical factors when assessing futility was undertaken. However, while expressing strong views about futility, the doctors in this study showed no unwillingness of express their views, indeed, quite the opposite. The pilot consultants had perhaps been over cautious with their warnings. This may be explained by the fact that they were all neurologists, the sub-specialism found in this study to be most cautious about the use of futility in difficult decisions for disabled children.

Figure 36: Use of futility and sub-specialties

Presented as a percentage of each sub-specialty

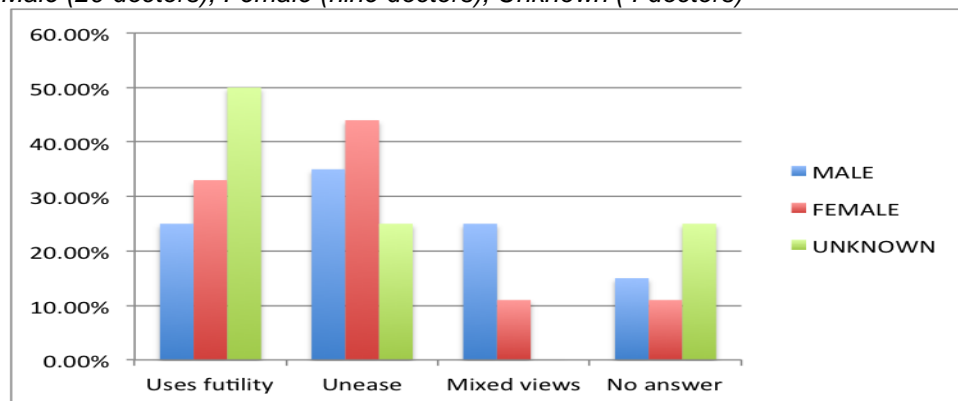
PICU (10 doctors); Neurology (nine doctors); Other Doctors (14 doctors)



4.5 How do male and female doctors compare on futility?

The responses given by male and female doctors about futility were also compared using the same methodology. Five male doctors (25%) were positive about its use compared with three female doctors (33%). Seven male doctors (35%) expressed unease compared with four female doctors (44%). Five male doctors (25%) took a mixed position, seeing some positives and some negatives in its use, but only one female doctor (11%) did so. While the disparity in numbers of male and female doctors in this study makes drawing any firm conclusions about difference in approach between doctors of different gender difficult, there does seem to be some suggestion that the female doctors were slightly more inclined to express a view either in favour or against the use of futility, than the male doctors.

Figure 37: Use of futility and gender
 Presented as a percentage of each gender
 Male (20 doctors); Female (nine doctors); Unknown (4 doctors)

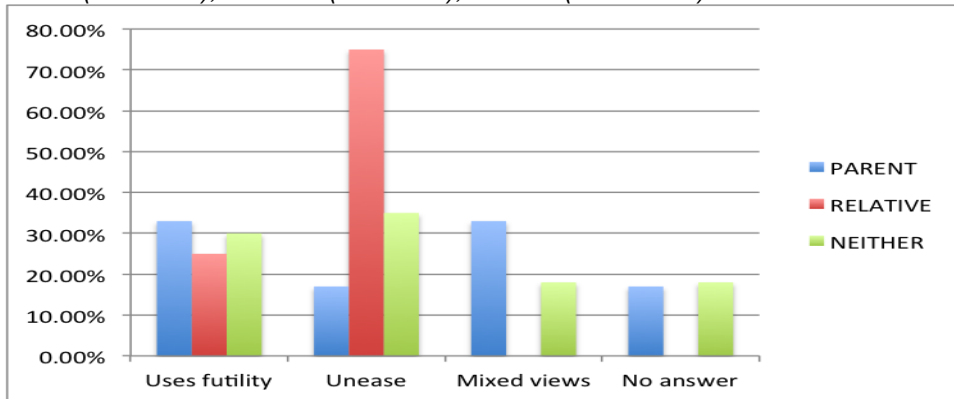


4.6 How do doctors with different personal experience of disability compare in their approaches to futility?

The responses on futility given by doctors classified by their personal experience of disability were also compared using the same methodology.

Three relative doctors (75%) expressed unease at futility being used as a factor in these decisions. In contrast, unease was expressed by just eight no-experience doctors (35%) and one parent doctor (17%). There was less diversity of opinion for doctors who were positive about futility being used, with two parent doctors (33%); seven no-experience doctors (30%) and one relative doctor (25%) indicating this. No relative doctor had a mixed view, but the same number of parent doctors (two/33%) held mixed viewpoint as were positive about futility. Once again, the diversity of views between the doctors here, which is striking, as it seems to suggest that personal and professional factors related to the doctor, rather than factors relating to the child are potentially impacting on how decisions are made for disabled children.

*Figure 38: Use of futility and personal experience of disability
Presented as a percentage of doctors by personal experience of disability
Parent (6 doctors); Relative (4 doctors); Neither (23 doctors)*



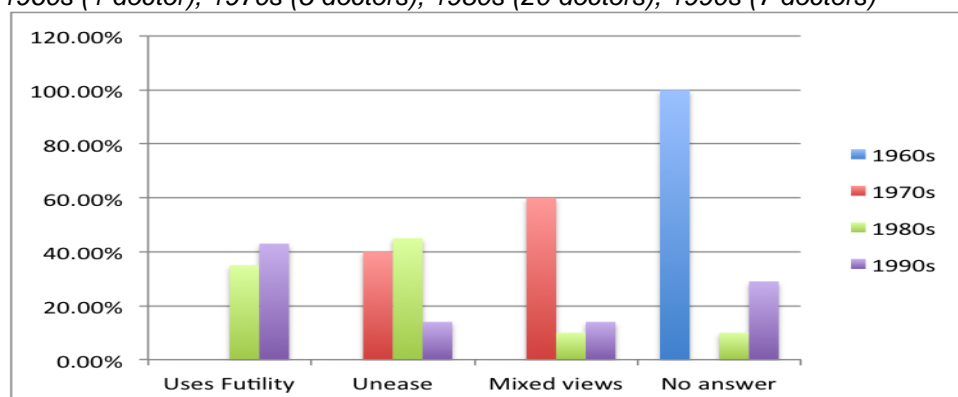
4.7 How do the different generations of doctors compare in their approaches to futility?

Consideration was also given as to whether doctors who qualified in different decades approached futility as a factor the same or differently.

The doctors' responses seem to suggest that doctors who qualified in different decades approached futility differently. All the doctors who gave answers suggesting futility played an important part in his or her decisions qualified between 1980 and 1993. The doctors who qualified earlier either expressed unease or did not answer the question. This seems to parallel the findings reported earlier regarding prognosis, with doctors who qualified earlier seeming to put less weight when making difficult decisions on both prognosis and futility, than their more recently qualified colleagues. None of the 1970s qualifiers indicated they viewed futility positively, while two (40%) indicated unease and three (60%) indicated mixed views. In contrast, seven 1980s qualifiers (35%) and three 1990s qualifiers (43%) were positive about futility. Nine 1980s qualifiers (45%) indicated unease with futility, but just one 1990s qualifier (14%) was uneasy about its use. Two 1980s qualifiers (10%) and one 1990s qualifier (14%) held mixed views. Again, it seems from this study that more recently qualified consultants approach at least some aspects of difficult decisions for disabled children differently from their older colleagues, suggesting as

mentioned earlier,⁶³² that perhaps the hidden curriculum does not have as much impact on decisions for disabled children as might be expected.

Figure 39: Use of futility and duration of practice
Presented as a percentage of doctors qualifying in each decade
1960s (1 doctor); 1970s (5 doctors); 1980s (20 doctors); 1990s (7 doctors)



4.8 How do doctors with and without religious faith compare in their approaches to futility?

The doctors' responses were also examined using the same methodology to explore whether there was any suggestion in the data that doctors who practice a religious faith approach futility differently from doctors who do not have a faith.

While four religious doctors (22%) expressed positive views about futility this increased to seven for non-religious doctors (53%). Likewise, while eight religious doctors (44%) expressed concerns about using futility, three non-religious doctors (21%) also did so. As other studies have found,⁶³³ the doctors' here, seem to suggest that religious doctors may approach difficult decisions, or certain aspects of them, differently from non-religious doctors. This does seem to add weight to the concerns expressed in the Kennedy Debate. It is difficult to

⁶³² Chapter five para 3.7, pp. 194-195

⁶³³ Cuttini, M, Nadai, M, Kaminski, M, Hansen, G, de Leeuw, Lenoir, S, Persson, J, et al (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries, *The Lancet* 355.9221: 2112-2118

think of a cogent argument as to why the religious beliefs of a doctor should impact on a patient's treatment, especially if the patient or the patient's family have no knowledge of or choice in this.

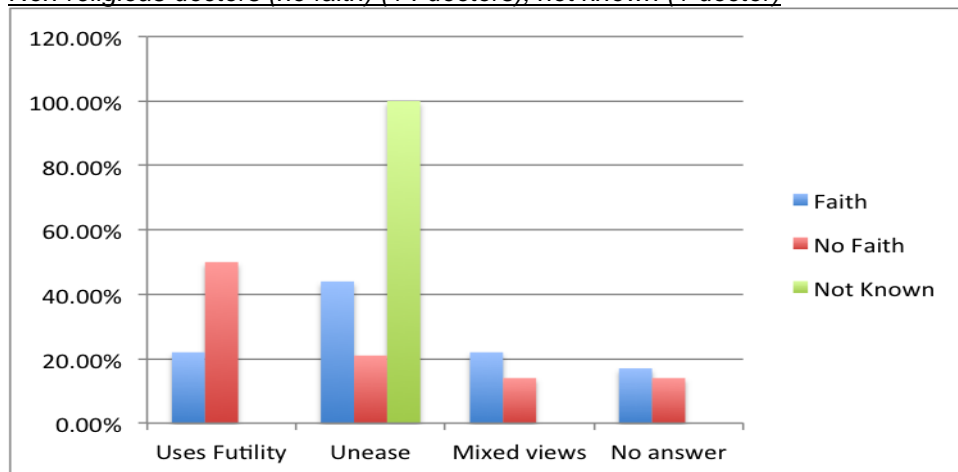
It will be recalled, as was seen in chapter four⁶³⁴ two doctors were particularly critical of parents allowing their religious beliefs to influence their views as to their child's best interests. No doctor in this study, however, expressed similar concern concerning a doctor's religious beliefs.

To summarise the findings from this study on futility, the data suggests that a doctor's personal and professional characteristics potentially impact on the weight a doctor puts on futility, although the results for futility were less clear cut than for prognosis. PICU consultants seem more inclined to put weight on futility than neurologists, as did non-religious doctors. 1970s qualifiers were less likely to put weight on futility as were relative doctors. With further questions on futility it may have been possible to discover whether doctors were considering quantitative or qualitative futility and the extent to which the differences found here can be explained because futility was being used and understood by different doctors in different ways.

⁶³⁴ Chapter four, para 5.4, p.172

Figure 40: Futility and a doctor's faith

Presented as a percentage of doctors in each category: religious doctors (faith) (18 doctors); Non-religious doctors (no faith) (14 doctors); not known (1 doctor)



Consideration is now given as to what doctors wrote about the use of quality of life as a factor in their decisions in their survey responses.

5. Quality of Life

5.1 Defining Quality of Life

As mentioned earlier, there are clear links between qualitative futility and quality of life assessments, so what the doctors said about quality of life can be read as also being relevant to their assessments of futility.

The World Health Organisation defines 'Quality of Life' as:

'individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.'⁶³⁵

However, when talking about 'quality of life' the doctors in this study may possibly, indeed are likely, to use the term in a range of different ways.

⁶³⁵ World Health Organisation; Measuring Quality of Life: WHO/MSA/MNH/PSF/97.4; 1997; www.who.int/mental_health/media/686.pdf last accessed 23 June 2016

5.2 Weight attributed to quality of life

The doctors were asked two questions about quality of life, the first being ‘what impact does a child’s quality of life have on these decisions?’ and the second being ‘if you assess a child’s quality of life, what factors do you feel are relevant to this assessment?’

As with futility, the pilot paediatricians had identified quality of life as a controversial topic in these decisions. The purpose of the first question was therefore to canvas the views of the doctors as to role of quality of life in these decisions and, in particular, the weight the doctors attribute to quality of life as a factor.

It will be recalled that Kennedy argued that quality of life assessments have no place in doctors’ decision-making.⁶³⁶ With this in mind, what is perhaps most striking about the doctors’ responses, is the strength of doctors’ views both for and against the use of quality of life in difficult decisions for disabled children. Nineteen doctors (57%) stated categorically that quality of life was one of, if not the most important issue when deciding for disabled children. It is perhaps noteworthy that this is six more doctors than those who cited quality of life as a factor in response to the earlier survey question, asking doctors which factors they consider when making difficult decisions for disabled children. This suggests that the doctors’ initial list of factors was not a complete one. Doctors who described quality of life as an important factor said, for example that it was:

Dr 3 (Other)

“Most important”

Dr11 (PICU)

“Major”

Dr 19 (neurologist)

“fundamental”

⁶³⁶ Chapter two, para 2, p.33

Dr 29 (neurologist)

“critical”

In contrast seventeen doctors (52%) expressed caution about its use when making a difficult decision for a severely disabled child. For example:

Dr 1 (neurologist):

“in practice, often a subjective judgment particularly of perceived pain, whilst recognising that in some fields (e.g. muscular dystrophy) research has shown that professionals consistently under estimate ‘quality of life’ in relation to the boy’s own assessment of this.”

Dr 12 (PICU)

“Quality of life is very difficult to judge”

Dr 15 (PICU)

“QoL is a subjective concept.”

and

Dr 24 (neurologist)

“A child’s quality of life is of great importance but can very difficult to assess and again there often (sic) differences in the perceptions of professionals and others e.g. family members and non-health professionals.”

Some doctors expressed their concerns more strongly.

For example:

Dr 9 (neurologist)

“I am deeply suspicious of clinician opinion on quality of life.”

Dr 8 (metabolic)

“I resist value judgments on quality of life”

The doctors in this survey therefore suggested that almost forty years on from Kennedy’s Astor lecture⁶³⁷ that the use or not of quality of life as a factor when deciding for a disabled child, is controversial amongst paediatrician.

⁶³⁷ Kennedy, I, (1979) *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form in Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

5.3 How is quality of life assessed?

The purpose of the second question asked about quality of life: *'if you assess a child's quality of life, what factors do you feel are relevant to this assessment?'* was to gain an insight into *how* doctors assess a child's quality of life. The doctors' answers to this question give an insight into not just how doctors make an assessment in practical terms, but also into how they define and understand the concept. Are they, for example, using to term to talk about clinical factors⁶³⁸ such as pain or are they talking about more nebulous concepts, non-clinical factors, such as the child's happiness; life at home and school; ability to communicate and such like? This distinction is of course an important one for the Kennedy Debate. Clinical factors can be more readily seen than non-clinical factors as part of the unique expertise and experience of a doctor. Using the definition of clinical and non-clinical factors presented in the last chapter,⁶³⁹ the doctors' responses show that seventeen doctors (51%) include both clinical and non-clinical factors when determining a child's quality of life.

For example:

Dr 3 (Other)

"Evidence of pleasure; is the child in pain or likely to become in pain due to intervention. Parental ability to cope with additional support. Likelihood of needing increased hospitalisation. Can the child be cared for in more comfort and with less pain if palliation instituted instead."

Dr 29 (neurologist)

"Pain and discomfort; ability to play, interact"

However, all the doctors who cite a combination of both clinical and non-clinical factors, cited many more non-clinical than clinical factors, for example:

⁶³⁸ Chapter four, para 2, pp.139-141

⁶³⁹ Ibid

Dr 2 (PICU)

“Independence, comfort and pain free, joy, happiness, enjoyment, interaction with others and how much time others have to give them”

Dr 17 (PICU)

“Can he show pleasure; how much life is spent in pleasure compared with pain?”

Seven doctors (21%) cited just non-clinical factors, for example:

Dr 27 (Other)

“family view; parents view; school environment; ‘happiness.’”

Dr 13 (Other)

“Level of dependence and expression of needs, ability to participate in family life, ability to experience pleasure.”

Two doctors (6%) cite just clinical factors, for example, Dr 1 (neurologist) who cited *“perceived pain”*, but qualified his answer by commenting that doctors are not good at accurately assessing this. Pain can however, be distinguished from non-clinical factors, such as a child’s happiness, as doctors are trained to assess pain and provided with tools to make such an assessment.

The doctors listed factors arguably not just beyond the unique education, training and competence of the doctor, but also beyond a doctor’s knowledge, unless the doctor consults with others, for example education staff; the child’s parents and where possible, the child. Fifteen doctors (45%) said they sought parents’ views as to their child’s quality of life; three doctors (9%) said they sought other health professionals’ views; four (12%) said they sought the child’s view and just two doctors (6%) said they sought the views of non-health professionals, such as teachers or social workers. Moreover, the doctors who sought the views of parents are the same doctors who sought the views of other parties, suggesting the majority of doctors in this study assess a child’s quality of life without consulting with others.

An important argument for this thesis is the differences between making decisions for disabled children when compared to infants. Most notably, far

more information, it is argued, is known about a child than an infant. This is particularly important here. For example, the pattern of the child's illness; how well the child communicates and interacts with family and friends; details of the child's education; the child's day to day routine and activities; and how well the child copes with his or her health problems and impairments, would in many cases be documented and readily available from a range of parties including the child, his or her parents, wider family, care and education staff, in a way such information will not be for infants. As was seen in chapter two,⁶⁴⁰ the Nuffield Council on Bioethics Working Party,⁶⁴¹ emphasised the uncertainty inherent in best interest decisions for neonates, with factors such as the extent of an infant's health, physical and cognitive impairment being little more than speculation. In contrast, for children, the more so the older the child, speculation of this kind will often not be needed as this information will be available. However, the doctors' responses seem to suggest that potentially for more than half the doctors in this study, rather than seeking this information from other parties, doctors seem to make assumptions about a child's quality of life. It is unclear from the doctors' responses, upon what their assumptions are based. This was a concern raised by doctors themselves in their interviews, as will be seen in chapter six.⁶⁴²

The wide range of factors doctors say they include when assessing quality of life, suggest that doctors are in effect using it as a proxy for a child's best interests. Many of the factors doctors list, such as a child's happiness, or whether a child attends school, could be classified as the 'wider welfare issues',⁶⁴³ the courts and the doctors' professional guidance advocate including

⁶⁴⁰ Chapter two, para 6, pp.54-55

⁶⁴¹ Nuffield Council (2006) *Critical Care Decisions in fetal and neonatal medicine: ethical issues*. Nuffield Council on Bioethics, London

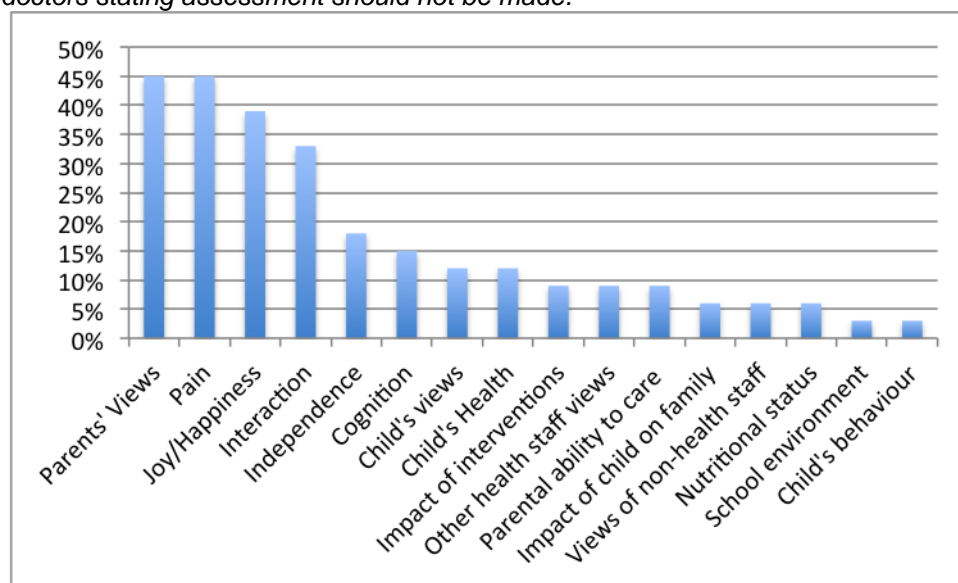
⁶⁴² Chapter six, para 7, pp.261-282

⁶⁴³ *Re OT* [2009] EWHC 633 (Fam), Para 98

in best interest decisions. Figure 41 illustrates the range of factors the doctors identified.

Figure 41: Factors doctors cite as relevant to Quality of Life assessments

Presented as a percentage of all doctors (33) with some doctors citing multiple factors and three doctors stating assessment should not be made.



It will be noted that these factors include the views of other parties. Fifteen doctors (45%) cited parents' view. Three doctors (9%) indicated they include a parent's ability to care for a child as a factor, which while no doubt impacting on a child's quality of life, is perhaps controversial. It is unclear both why this should be deemed relevant and on what basis the doctors are making the decision. For example, is it based on a doctor's subjective opinion of a parent's ability to cope or on something else? This does seem to be a prime example of the type of decision cited by Kennedy as being beyond the legitimate competence of a doctor, as discussed in chapter two.⁶⁴⁴

5.4 How do the sub-specialties compare on quality of life?

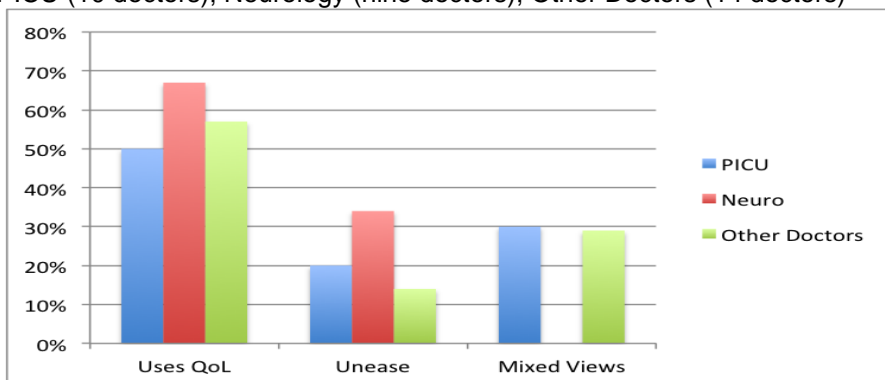
Using the methodology outlined earlier, the doctors' answers on quality of life were compared by sub-specialty. As can be seen from figure 42, some small

⁶⁴⁴ Chapter two, para 2, pp.25-34

differences in the weight doctors' place on quality of life are seen between the three sub-specialty groups. Six neurologists (67%), five PICU consultants (50%) and eight Other Doctors (57%), were all positive about its use. Three neurologists (33%); two PICU consultants (20%) and two Other Doctors (14%) all expressed concerns at quality of life being used. The neurologists were very clear cut in their responses, either being very positive about quality of life or expressing strong concerns. In contrast three PICU consultants (30%) and four Other Doctors (29%) gave mixed answers expressing some ambivalence about its use. The reason for this is unclear from the doctors' responses, but could be, as discussed earlier, the neurologists are more likely to have long term relationships with the children and broader knowledge of their lives. It may also be because the different groups understood and used the term differently.

Figure 42: Use of quality of life and sub-specialities

Presented as a percentage of each sub-speciality
 PICU (10 doctors); Neurology (nine doctors); Other Doctors (14 doctors)

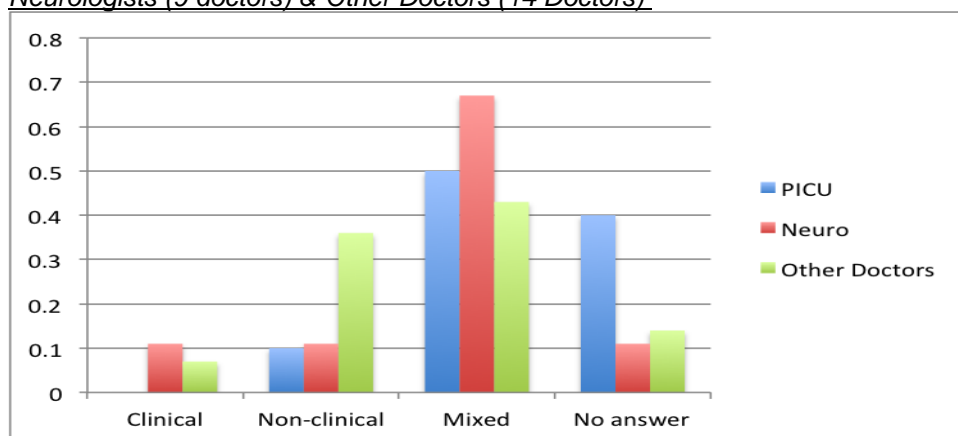


To explore whether this was the case, the doctors also answered the question 'if you assess a child's quality of life, what factors do you feel are relevant to this assessment?' The doctors' answers were, once again, analysed to examine the extent to which doctors cited clinical and non-clinical factors as defined in the last chapter.⁶⁴⁵ The doctors' responses suggest that as with prognosis, the neurologists seem at least slightly more inclined to use clinical factors in their assessment of quality of life, especially when compared PICU consultants,

⁶⁴⁵ Chapter four, para 2, pp. 139-142

although the differences here are small. While one neurologists (11%) cited purely clinical factors as those they use when assessing quality of life, none of the PICU consultants did so. One Other Doctor (7%) cited just clinical factors. When the percentage of doctors who use just non-clinical factors for their assessment of quality of life is explored, similar percentages of neurologists one (11%) and PICU consultants (one doctor) (10%) were found to do so. This compares with five Other Doctors (36%) who cited purely non-clinical factors. Far more doctors gave a mixed answer including both clinical and non-clinical factors when writing about quality of life than prognosis. Six neurologists (67%); five PICU consultants (50%) and six Other Doctors (43%) all gave mixed answers. Figure 41⁶⁴⁶ earlier showed the range of factors doctors cited, suggesting that quality of life was perhaps, as suggested earlier, used by doctors as a proxy for best interests, with different doctors factoring in different aspects of a child's health and wider welfare issues, into their definition of quality of life.

Figure 43: Use of clinical and non-clinical factors in doctors' quality of life assessments Presented as a percentage of doctors from each sub-specialty group: PICU (10 doctors); Neurologists (9 doctors) & Other Doctors (14 Doctors).



5.5 How do male and female doctors compare on quality of life?

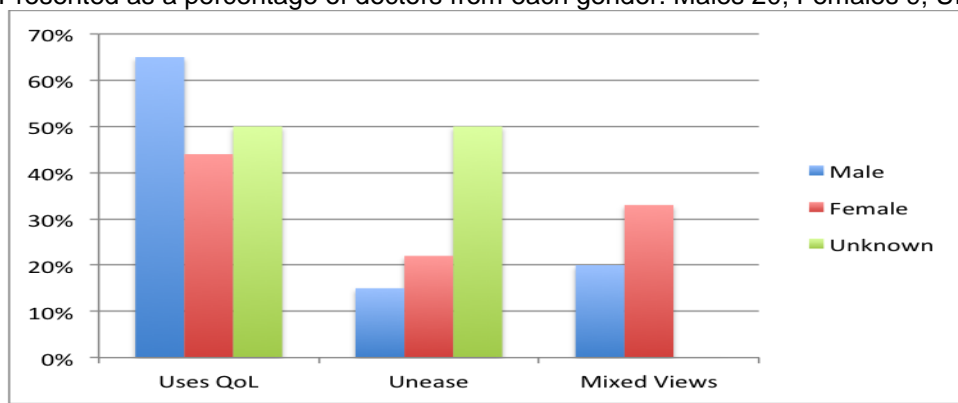
The responses given by male and female doctors about quality of life were also compared using the same methodology as before, to ascertain whether there was any difference in the responses given. The doctors' answers suggest that

⁶⁴⁶ Figure 41, p. 213 ante

the male doctors are potentially more inclined to include quality of life in their decisions than female doctors. Thirteen male doctors (65%) gave answers putting considerable weight on quality of life compared with four female doctors (44%). Three male doctors (15%) expressed concerns about the use of quality of life and two female doctors (22%). Three female doctors (33%) and four male doctors (20%) expressed mixed views. The doctors did not provide enough information to explain these differences and as with earlier findings, the low number of female doctors in this study compared with male doctors may be impacting on these findings.

Figure 44: Use of quality of life and gender

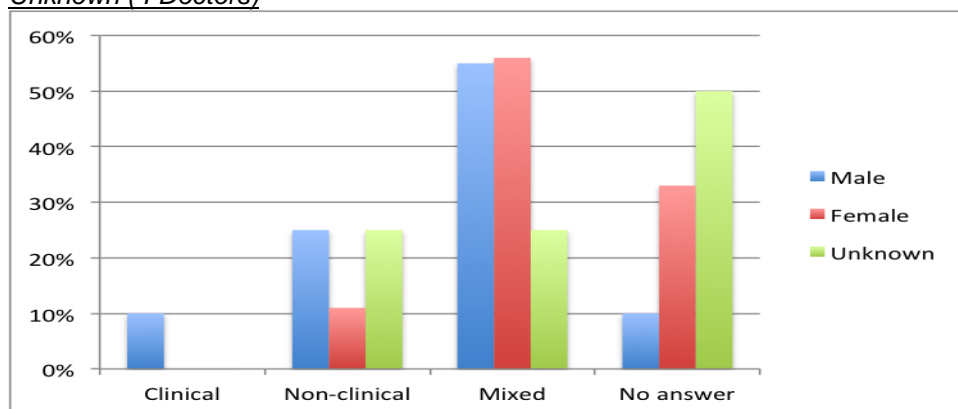
Presented as a percentage of doctors from each gender: Males 20; Females 9; Unknown 4



The doctors' responses were also examined to consider whether male and female doctors show any difference in their use of clinical or non-clinical factors. While two male doctors (10%) used solely clinical factors to make their quality of life assessments, none of the female doctors did so. Nine male doctors (45%) used clinical factors to some degree compared with three female doctors (33%). Three male doctors (15%) used non-clinical factors compared with four female doctors (44%). However, the majority of doctors and similar percentages of male (eleven/55%) and female (five/56%) doctors used both clinical and non-clinical factors in their quality of life assessments. This suggests that, as with prognosis, a doctor's gender does not seem to be an important influence on how a doctor uses quality of life. However, once again it is recognised that the

disparity between the number of male and female doctor in this study makes comparison difficult.

Figure 45: Use of clinical and non-clinical factors in doctors' quality of life assessments Presented as a percentage of male and female doctors: male (20 doctors); female (9 doctors) & Unknown (4 Doctors)



5.6 How do doctors with different personal experience of disability compare in their approaches to quality of life?

The doctors' responses on quality of life classified by their personal experience of disability were also compared using the same methodology. The data seems to suggest that doctors who have personal experience of disability are perhaps more likely than doctors who do not, to use quality of life as a factor in these decisions. Four parent doctors (67%) expressed views suggesting they strongly favoured the use of quality of life as a factor, as did three relative doctors (75%). This compares with twelve no-experience doctors (52%). None of the parent doctors and none of the relative doctors expressed a mixed view, compared with seven no-experience doctors (31%). This suggests that doctors who have personal experience of disability favour the use of quality of life as a factor when compared with doctors with no personal experience of disability. It will be recalled from chapter two,⁶⁴⁷ that Basnett,⁶⁴⁸ a doctor and disability advocate, like Kennedy, was critical of doctors including quality of life

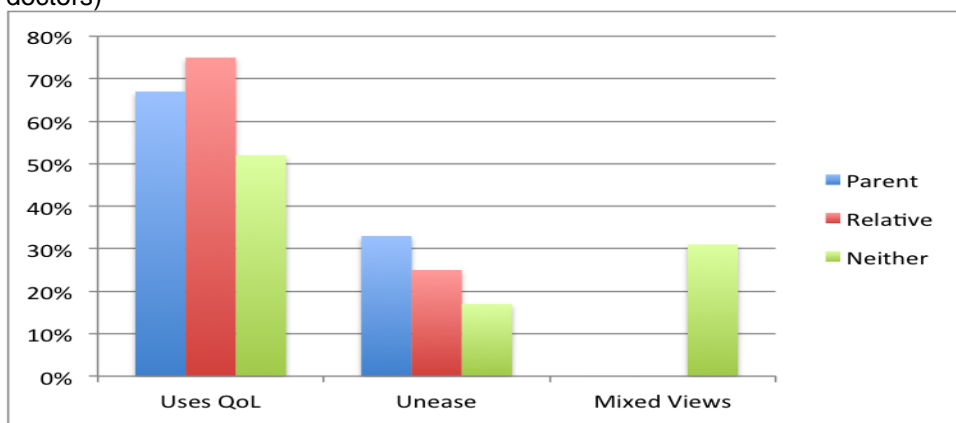
⁶⁴⁷ Chapter two, para 10, p. 87-91

⁶⁴⁸ Basnett, I, (2001) 'Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467

assessments in their best interest decisions. It might then be expected that similar concerns be expressed by doctors with personal experience of disability. The doctors in this study suggest otherwise. There are a number of possible reasons for this. The doctors in this study, unlike Basnett are not disabled themselves and it is perhaps wrong to assume that a relative of a disabled person will adopt the same viewpoint as a disabled person. Moreover, a distinction needs to be drawn between deciding based on a disabled child's *actual* quality of life, which may or may not be controversial and the decisions Basnett criticises, those made, based on prejudicial assumptions about a disabled person's quality of life, which are more clearly controversial, being based on prejudice rather than fact. It will be seen in the next chapter, that in their interviews, doctors who were critical of colleagues who made quality of life decisions, seemed to be mostly criticising decisions based on prejudicial assumptions of quality of life, rather on actual quality of life.⁶⁴⁹

Figure 46: Quality of life and personal experience of disability

Shown as a percentage of total of Parents (6 doctors) Relatives (4 doctors) Neither (23 doctors)



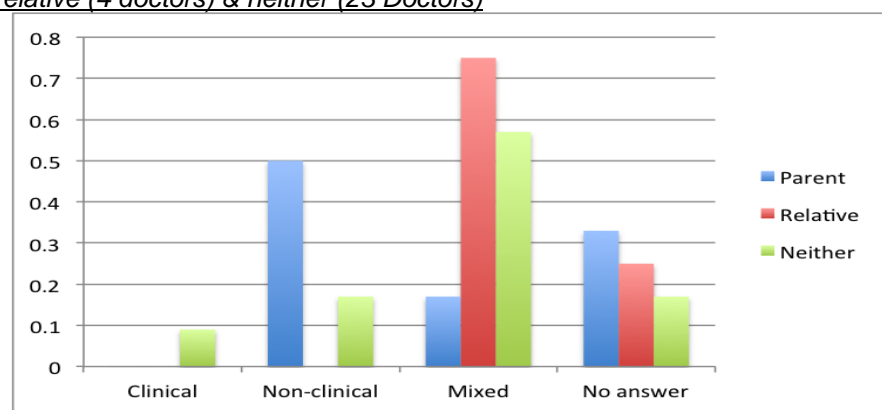
The doctors' responses were also examined to consider whether there is any difference in the extent to which the three groups of doctors included clinical or non-clinical factors when evaluating a disabled child's quality of life. As can be seen from figure 47, while three no-experience doctors (9%) used just clinical factors, none of the parent doctors or relative doctors, did so. Three parent

⁶⁴⁹ Chapter six, para 7.1, p. 262-266

doctors (50%) however used just non-clinical factors in their assessments of a disabled child's life. This again suggests that quality of life is perhaps being used as a proxy for best interests to draw on a child's wider welfare, as well as medical factors. Three relative doctors (75%) used both clinical and non-clinical factors as did thirteen no-experience doctors (57%) and one parent doctor (17%). Four no-experience doctors (17%) also reported using just non-clinical factors. None of the relative doctors did so.

Although the pool of doctors here is comparatively small, the data does suggest that quality of life is a particularly controversial factor for paediatricians. Doctors with a personal connection with disability seem in particular to have a strong view for or against its use, paralleling the position of neurologists, the doctors with the most professional experience of disabled children. The doctors with a personal connection with disability also, however, seem more likely to favour quality of life and also to include non-clinical factors in their assessments, suggesting, they in particular use quality of life as a proxy for best interests.

Figure 47: Use of clinical and non-clinical factors in doctors' quality of life assessments & personal experience of disability. Presented as a percentage of doctors' personal experience of disability: parent (6 doctors); relative (4 doctors) & neither (23 Doctors)



5.7 How do different generations of doctors compare in their approaches to quality of life?

Consideration was also given as to whether doctors who qualified in different decades approached quality of life as a factor the same or differently. There

was noticeable similarity in the data between doctors who qualified in the 1970s and 1980s. Three 1970s qualifiers (60%) and twelve 1980s qualifiers (60%), were positive about using quality of life. One 1970s qualifier (20%) and four 1980s qualifiers (20%) expressed unease at the use of quality of life. Twenty percent of doctors from each of these decades also suggested mixed feelings towards the use of quality of life. This consistency contrasts with the differences in approach of doctors from the 1970s and 1980s towards prognosis and futility.

The 1990s qualifiers showed a slight shift in approach to quality of life with three (43%) expressing support for its use; two (29%) expressing concern and two (29%) expressing mixed views. This contrasts with the earlier findings concerning the doctors' use of futility, where 1990 qualifiers seemed more likely to use the factor than earlier qualifiers. This perhaps suggests that 1990s qualifiers are using futility quantitatively rather than qualitatively, not using it as a synonym for quality of life discussed here. Two of the older doctors later interviewed discussed the shift in approaches generally from more experienced to new consultants, as will be seen in the next chapter.⁶⁵⁰

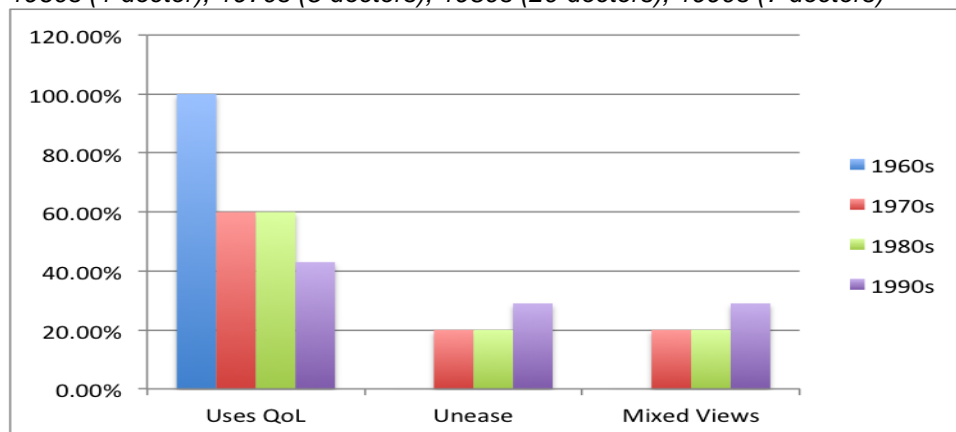
Differences in approaches here between different generations of doctors is perhaps another indication that the hidden curriculum is impacting on doctors' decision making for disabled children less than might be expected, with 1990 qualifiers seeming to be more influenced in their decision making for disabled children by factors other than the hidden curriculum. What these factors might be considered in chapters six⁶⁵¹ and nine.⁶⁵²

⁶⁵⁰ Chapter six, para 7.1.3, p.267-268

⁶⁵¹ Ibid

⁶⁵² Chapter nine, para 3.4, pp.374-378

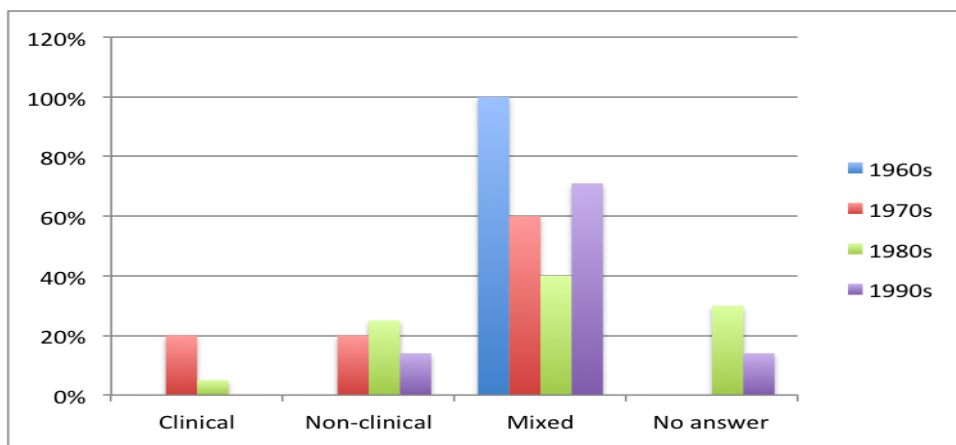
*Figure 48: Use of quality of life and duration of practice
Presented as a percentage of doctors qualifying in each decade
1960s (1 doctor); 1970s (5 doctors); 1980s (20 doctors); 1990s (7 doctors)*



When the data is further examined to explore whether duration of practice seems to impact on whether a child's quality of life is assessed as a clinical or non-clinical factor, small differences can be found. One doctor from each of the 1970s and 1980s listed solely clinical factors, this represented 20% of 1970s qualifiers but 5% of 1980s qualifiers. No 1990s qualifier listed solely clinical factors, suggesting overall few doctors listing purely clinical factors. One 1970s qualifier (20%) and five 1980s qualifiers (25%), cited just non-clinical factors, as did one 1990s qualifier (14%). The majority of 1970s qualifiers and 1990s qualifiers cited both clinical and non-clinical factors, as those they consider when assessing quality of life; with three 1970s qualifiers (60%) and five 1990s qualifiers (72%) doing so. In contrast, fewer than half of the 1980s qualifiers (eight /40%) cited both clinical and non-clinical factors in their assessments. However, six 1980s qualifiers (30%) and one 1990s qualifier (14%) did not answer the question. This included doctors who had expressed unease at quality of life being used as a factor when deciding for a disabled child. The prevalence of doctors from all decades who use both clinical and non-clinical factors when assessing the quality of life of a disabled child, over those that use either just clinical or just non-clinical factors, does seem to support the contention that doctors are using quality of life widely, as a proxy for best interests in these decisions, drawing as the doctors do when assessing quality of life, on a range of medical and welfare factors. The consistency

between doctors from the 1970s and 1980s is noticeable, as is the slight shift towards more 1990s qualifiers feeling uneasy at the use of quality of life as a factor. There is not sufficient information in the doctors' survey responses to explain this shift. However, as mentioned, older generation doctors did discuss this in their interviews.⁶⁵³

Figure 49: Use of clinical and non-clinical factors in doctors' quality of life assessments & duration of practice. Presented as a percentage of doctors qualifying in each decade 1960s (1 doctor); 1970s (5 doctors); 1980s (20 doctors); 1990s (7 doctors)



5.8 How do doctors with and without religious faith compare in their approaches to quality of life?

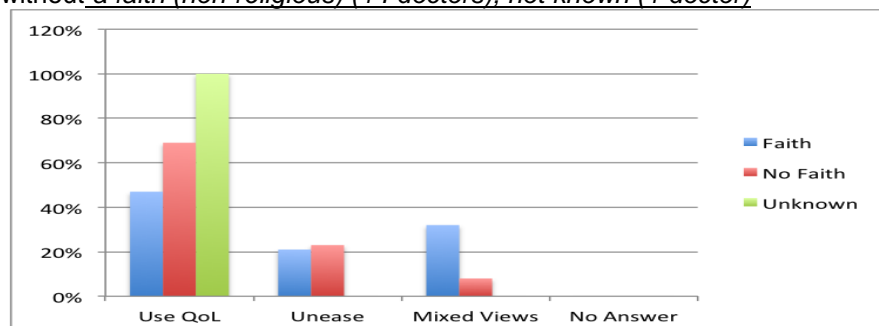
The doctors' responses were also examined using the same methodology to explore whether there was any suggestion in the data that religious doctors approach quality of life as a factor differently from non-religious doctors. The doctors' responses do suggest some difference with nine non-religious doctors (69%) giving positive responses about its use, compared with nine religious doctors (47%). However, similar percentages of religious and non-religious doctors expressed significant unease about using quality of life, with four religious doctors (21%) and three non-religious doctors (23%) doing so. Religious doctors seem more likely to have mixed views (six/32%) compared with non-religious doctors (seven/8%).

⁶⁵³ Chapter six, para 7.1.3, pp.267-268

A doctor's religious faith, therefore, does seem potentially to impact on a doctor use of quality of life, as well as prognosis and futility, in these decisions for disabled children. This, as was seen in chapter four⁶⁵⁴ is in keeping with findings from larger studies such as Cuttini et al,⁶⁵⁵ a pan-European study of neonatologists which, as will be recalled, found doctors' religious beliefs to influence whether or not they withdrew treatment from neonates.

This finding adds further weight to the Kennedy debate as the legitimate relevance of a doctor's religion (or non-religion) to a child patient's best interests is arguably difficult to establish. As Wilkinson & Truog⁶⁵⁶ (a paper discussed in more detail in chapter six),⁶⁵⁷ suggest, if personal morality plays a part in best interest decisions, it should be the morality of the patient or patient's family in the case of a child whose views cannot be ascertained, not that of the doctor.

*Figure 50: Use of quality of life and a doctor's faith
Presented as a percentage of doctors in each category: follow a faith (religious) (18 doctors); without a faith (non-religious) (14 doctors); not known (1 doctor)*



The doctors' responses were also examined to consider whether religious doctors and non-religious doctors showed any difference in their use of clinical or non-clinical factors when assessing a disabled child's quality of life. Two

⁶⁵⁴Chapter four, para 4, p.145-146

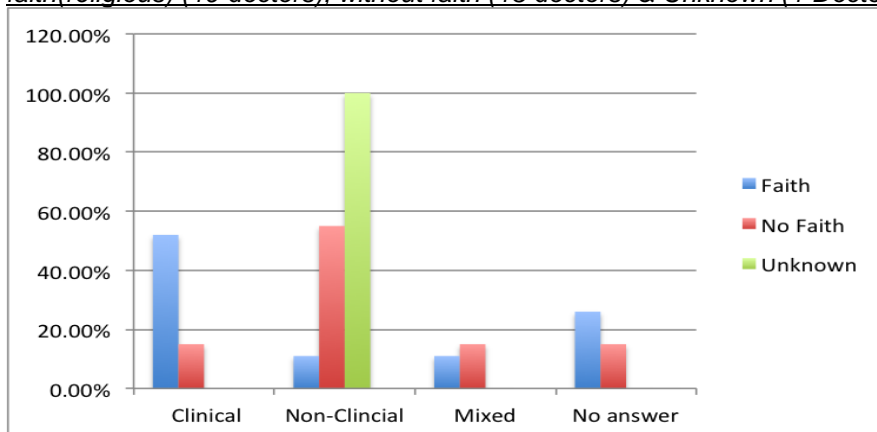
⁶⁵⁵ Cuttini, M, Nadai, M, Kaminski, M, Hansen, G, de Leeuw, Lenoir, S, Persson, J, et al (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries, *The Lancet* 355.9221: 2112-2118

⁶⁵⁶ Wilkinson, D, Truog, RD, (2013) The luck of the draw: physician-related variability in end-of-life decision-making in intensive care, *Intensive Care Medicine*, 39, 1128-1132

⁶⁵⁷ Chapter six, para 3.4, p.243

religious doctors (11%) listed just clinical factors, none of the non-religious doctors did so. The two groups of doctors were closer when it came to those who used solely non-clinical factors, with four religious doctors (21%) suggesting they did this and three non-religious doctors (23%) doing so. The non-religious doctors seemed more inclined to use a mixture of clinical and non-clinical factors with eight (62%) of them doing so, compared with eight of the religious doctors (42%). Five religious doctors (26%) and two non-religious doctors (15%) did not answer the question or gave an answer, which was unclear as to whether the doctor used clinical and/or non-clinical factors. As with prognosis and futility, the doctors' responses do tend to suggest that the religious doctors in this study were more inclined to use clinical factors than the non-religious doctors, who in turn seemed more inclined to use non-clinical factors when compared with the religious doctors.

Figure 51: Use of clinical and non-clinical factors in doctors' quality of life assessments & a doctor's faith. Presented as a percentage of doctors' with and without a religious faith (non-religious): with faith (religious) (19 doctors); without faith (13 doctors) & Unknown (1 Doctor)



To summarise the findings in relation to quality of life, it does seem that doctors are potentially using quality of life as a proxy for best interest decisions, especially the non-religious doctors. There is evidence of quality of life being used to evaluate wider welfare issues, not just clinical issues. Overall doctors do seem to put more weight on non-clinical aspects than clinical aspects of quality of life and there seems to be little consensus between doctors as to what they are or should be assessing when they assess a child's quality of

life. Indeed, there was no consensus between doctors as to whether quality of life should even be assessed as a factor in these decisions. The findings on quality of life seem to suggest further that while almost half of the doctors consult with other parties when assessing a child's quality of life, over half report not doing so. Consultation also seems to be limited in the cases, where it does happen, to the child's parents and rarely extend to others, such as a child's teacher who will often spend a lot of time with a child and be able to provide important evidence as to a child's quality of life. These findings do tend to support Kennedy's contention that doctors may be making decisions they are not trained or educated to make.

These findings also highlight a potential clash between the two lenses of the Kennedy Debate and best interest decision-making as outlined by the jurisprudence of the English High Court and doctors' professional guidance, used to analyse the doctors' decision in this study. While Kennedy was highly critical of doctors assessing a patient's quality of life, viewing such assessments as beyond the scope of a doctors' competence, as was seen in chapters two and four, the court and doctors' guidance instructs doctors to consider wider welfare issues, which would seem to include a child's quality of life. This conflict can perhaps be reconciled, if doctors making best interest decisions are seen as being in a quasi-judicial position. The doctor's job is then not to *decide* the child's best interests but to gather evidence from all relevant parties and balance this to *determine* a child's best interests, with other key parties, such as the child's parents and others closely involved in the child's care. It seems this conflict only arises if, as some of the doctors in this study suggest they do, a doctor makes the decision without this wide consultation and involvement. This question is returned to in chapter ten, when consideration is given as to whether a doctor or someone else should take on this quasi-judicial role when these decisions are being made.⁶⁵⁸

⁶⁵⁸ Chapter ten, para 5.2, pp.400-401

This chapter now explores what the doctors said about a child's cognitive ability as a factor in difficult decisions for disabled children.

6. Cognitive Ability

6.1 Defining cognitive ability

The BMJ's Best Practice Guide 'Assessment of learning difficulty and cognitive delay'⁶⁵⁹ states that intellectual impairment:

'may be either generalised (cognitive impairment) or specific to one area (learning difficulty)'.⁶⁶⁰

The guide defines children with cognitive impairment as children having an IQ below 70. It goes on to say:

'about 1% of children have cognitive impairment. Down's syndrome and foetal alcohol syndrome are among the most common identified causes of cognitive impairment'.⁶⁶¹

The guide also states that cerebral palsy, (as noted in chapter one,⁶⁶² the most common condition for the children considered by the doctors in this study)

'is not a cause of cognitive impairment. However, the two conditions can co-exist and for this reason a cause and effect relationship is often mistakenly assumed both by clinicians and the general public'.⁶⁶³

This may be significant for the children at the centre of this study for three reasons. It suggests that doctors may not be good at assessing a child's

⁶⁵⁹ BMJ (2016) *Assessment of learning difficulties and cognitive delay; Best Practice*, BMJ, London, <http://bestpractice.bmj.com/best-practice/monograph/884/diagnosis/step-by-step.html>; last accessed 20 July 2016

⁶⁶⁰ Ibid, summary

⁶⁶¹ Ibid

⁶⁶² Chapter One, para 2.3, p.4

⁶⁶³ BMJ (2016) *Assessment of learning difficulties and cognitive delay; Best Practice*, BMJ, London, <http://bestpractice.bmj.com/best-practice/monograph/884/diagnosis/step-by-step.html>; last accessed 20 July 2016

cognitive ability. This may mean assumptions are wrongly made that might impact on doctors' assessment of futility or quality of life, as doctors' responses suggest they make links between these factors. This makes cognitive ability as a factor, like futility and quality of life, particularly pertinent to the Kennedy Debate. Also, children who are competent may be excluded from decisions about their treatment and care.

It will be recalled from chapter four,⁶⁶⁴ that doctors are warned in their professional guidance against making prejudicial assumptions about a disabled child.⁶⁶⁵ It was also seen in chapter two,⁶⁶⁶ that repeated investigations have found that cognitively impaired patients can face particularly extreme difficulties in accessing NHS treatment and care, due largely to negative assumptions made by health professionals.

6.2 Weight attributed to cognitive ability

The doctors were asked 'what part does a child's cognitive ability play in these assessments?' As was seen with prognosis, futility and quality of life, the doctors in this study expressed a diversity of views as to the weight, which should be put on a child's cognitive ability when making difficult decisions for severely disabled children. Eight doctors (24%) described cognition as being an important factor in their considerations. This compared with eleven doctors (33%) who either stated they did not use a child's cognitive ability or placed very little weight on it. Four doctors (12%) saw cognitive ability only relevant to their decisions, to the extent a child's ability impacted on whether the child could to take part in the decision-making process.

⁶⁶⁴ Chapter four, para 3, p.142-143

⁶⁶⁵ RCPCH (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London para 2.7.1, p. 24

⁶⁶⁶ Chapter two, para 8, p.75-79

6.3 How is cognitive ability assessed?

The doctors were asked the question ‘if you make such an assessment, how do you make an assessment of a disabled child’s level of cognitive ability?’ Two doctors, Drs 21 and 32 (both Other), reported not making such an assessment. However, the same two doctors did later report being moderately confident in their ability to assess a child’s cognitive ability. Their responses can be read either as contradicting each other, or as the doctors reporting that they were confident of their ability to make an accurate assessment, but chose not or had not had a reason to make such an assessment.

The remaining thirty-one doctors (94%) described using observation; parental views; formal testing or the views of colleagues to assess a child’s cognitive level. Six doctors (18%) used a combination of two or more of these.

Eight doctors (24%) wrote that they sought the views of parents as to a child’s cognitive ability, six (18%) in combination with their own observation or formal testing. Six doctors (18%) mentioned some form of formal testing, such as Dr.7 (neurologist): “*clinical exam may need to be complemented by formal psychometry.*” Four doctors (12%) wrote that they sought advice from psychologists and just one doctor from education staff. As the children will mostly be in some form of education and as the cognitive ability of the children discussed can range from profound cognitive impairment to educationally able, it is perhaps surprising that doctors do not more often ask a child’s teacher or educational psychologist about a child’s cognitive level.

6.4 How do the sub-specialties compare on cognitive ability?

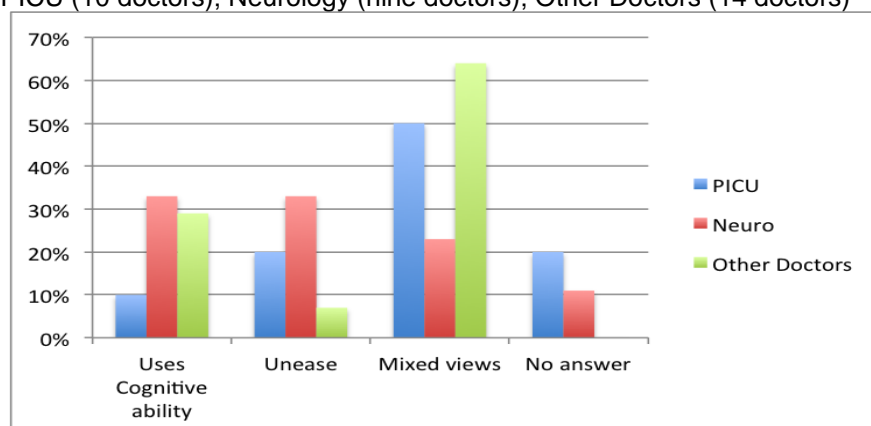
When the doctors’ answers are compared by sub-specialty using the methodology outlined earlier, as can be seen from figure 52, neurologists and Other Doctors seem to use a child’s cognitive ability in their difficult decisions more than PICU consultants. Three neurologists (33%) and five Other Doctors (29%) indicated they put considerable weight on cognition compared with one PICU consultant (10%). Neurologists as a sub-group made up four (66%) of the

doctors who said they formally tested cognition, the remaining being one PICU consultant (17%) and one Other Doctor (17%). This may explain why neurologists are more inclined to use cognition as a factor, as they are more likely to test it. Although neurologists appear to be more likely to use cognition as a factor than the other two sub-specialty groups, they are also the sub-specialty who were most likely to express unease at its use. The same number of neurologist (three/33%) reported unease as reported putting a lot of weight on cognition. Neurologists therefore seem to disagree amongst themselves as to whether a child's cognitive ability is relevant. More PICU consultants (two/20%) also expressed unease at its use than said they put weight on cognition as a factor (one/10%). In contrast, fewer (one/7%) of the Other Doctors expressed unease. The majority of Other Doctors (nine/64%) took a mixed view towards cognition, as did half of PICU consultants (five/50%). Fewer neurologists (two/22%), however, took a mixed approach than either put weight or expressed unease at the use of cognition. These results seem to suggest that neurologists are slightly more inclined to put weight on a child's cognitive ability, perhaps because they are the sub-specialty most likely to assess it. However, the results also seem to suggest the use or otherwise of a child's cognitive ability is contentious between doctors from the same sub-specialism, as well as amongst paediatricians generally.

Figure 52: Use of a child's cognitive ability and sub-specialties

Presented as a percentage of each sub-specialty

PICU (10 doctors); Neurology (nine doctors); Other Doctors (14 doctors)



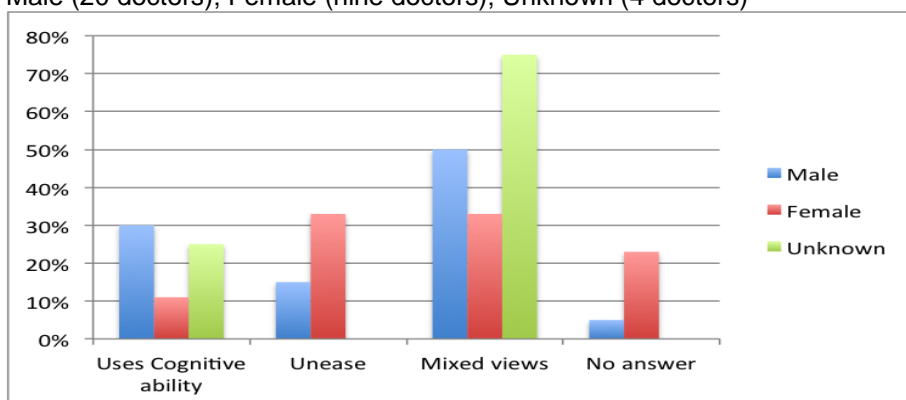
6.5 How do male and female doctors compare on cognitive ability?

The responses given by male and female doctors about a child's cognitive ability were also compared using the same methodology to ascertain whether there were any differences. Some difference in approach between male and female doctors were found, with six male doctors (30%) favouring its use compared with one female doctor (11%) and three female doctors (33%) expressing unease at its use compared with three male doctors (15%). Three female doctors (33%) expressed a mixed view towards the use of cognition, suggesting six female doctors (66%) had at least some reservations. This compares with ten male doctors (50%) who expressed a mixed view, suggesting a similar percentage (65%) of male doctors (thirteen doctors) also like the female doctors, had at least some reservations.

Figure 53: Use of a child's cognitive ability and gender

Presented as a percentage of each gender

Male (20 doctors); Female (nine doctors); Unknown (4 doctors)



6.6 How do doctors with different personal experience of disability compare in their approaches to the use of a child's cognitive ability?

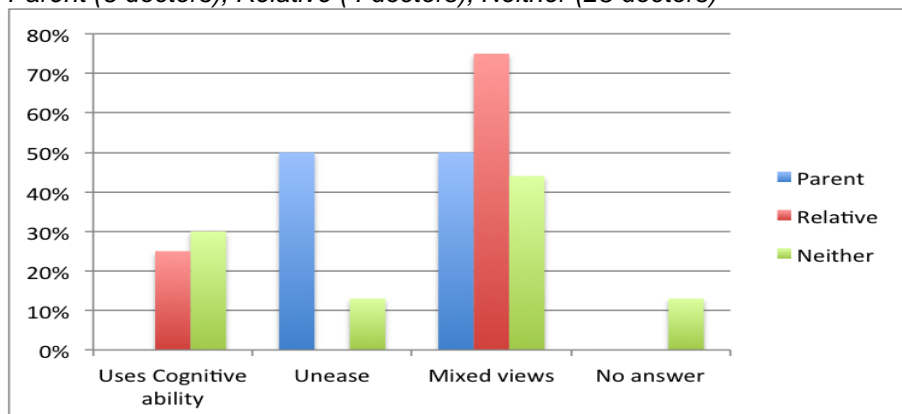
The doctors' responses about a child's cognitive ability were also classified by the doctors' personal experience of disability and compared using the same methodology.

It is noteworthy that none of the parent doctors expressed a view suggesting they put significant weight on a child's cognitive ability in their

decisions. However, one relative doctor (25%) and seven no-experience doctors (30%) suggested that they did so. Three parent doctors (50%) expressed unease at the use of a child's cognitive ability as a factor, whereas none of the relative doctors did. Only three no-experience doctors (13%) did so. Three relative doctors (75%) did however express a mixed view, suggesting at least some concern at its use as a factor, but also seeing some merit. Three parent doctors (50%) and ten no-experience doctors (43%) also expressed a mixed view.

This data seems to suggest that while the majority doctors had at least some unease about the use of the child's cognitive ability in these decisions, parent doctors seem more likely to express unease than their colleagues. What is perhaps noteworthy here, is that whereas the doctors who professionally have most experience of child disability, the neurologists, were marginally more likely than the other sub-specialisms to be positive about the use of a child's cognitive ability when making these decisions, none of the parent doctors who, are likely to have to most personal experience of child disability, were positive about its use. A possible reason for this is, as was seen earlier, neurologists were more likely to formally assess a child's cognitive ability, so perhaps some neurologists felt more inclined to use this factor than other paediatricians. However, this may also suggest that the circumstances or capacity in which experience is gained can make a difference to how doctors approach their difficult decisions for disabled children. Indeed, differences in approach were found between parent doctors and relative doctors were also found.

*Figure 54: Use of a child's cognitive ability and personal experience of disability
Presented as a percentage of doctors by personal experience of disability
Parent (6 doctors); Relative (4 doctors); Neither (23 doctors)*

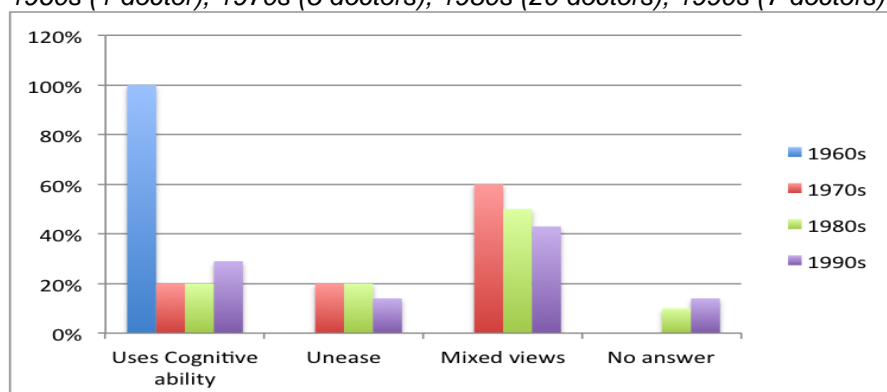


6.7 How do different generations of doctors compare in their approaches to a child's cognitive ability?

Consideration was also given as to whether doctors who qualified in different decades approached a child's cognitive ability as a factor the same or differently. As was seen with fertility, the doctors' responses suggest (when compared with other personal and professional characteristics) a remarkable level of consistency between doctors who qualified in the different decades, especially between doctors who qualified in the 1970s and 1980s. Once again there does seem to be a slight shift in approach for doctors who qualified in the 1990s, compared with those from the two preceding decades. One 1970s qualifier (20%) and four 1980s qualifiers (20%) were positive about the use of a child's cognitive ability in these decisions. This rises to two for 1990s qualifiers (29%). Likewise, one 1970s qualifier (20%) and four 1980s qualifiers (20%) expressed unease at its use, with this falling to one 1990s qualifier (14%). However, this data also suggests a lack of consensus between doctors generally, just that the extent of that lack of consensus seems to be consistent regardless of when doctors qualified. Most doctors expressed a mixed viewpoint, with three 1970s qualifiers (60%), ten 1980s qualifiers (50%) and three 1990s qualifiers (43%) doing so. There does seem to be a suggestion in the data that doctors who qualified most recently are less likely to have reservations about the use of cognitive ability as a factor than doctors to

qualified longer ago. This perhaps contradicts the suggestion made earlier, that more recently qualified doctors seem to possibly take a more child rights approach to difficult decisions for disabled children and be more cognisant of the legislative changes outlined in chapter two.⁶⁶⁷

Figure 55: Use of a child's cognitive ability and duration of practice
Presented as a percentage of doctors qualifying in each decade
1960s (1 doctor); 1970s (5 doctors); 1980s (20 doctors); 1990s (7 doctors)



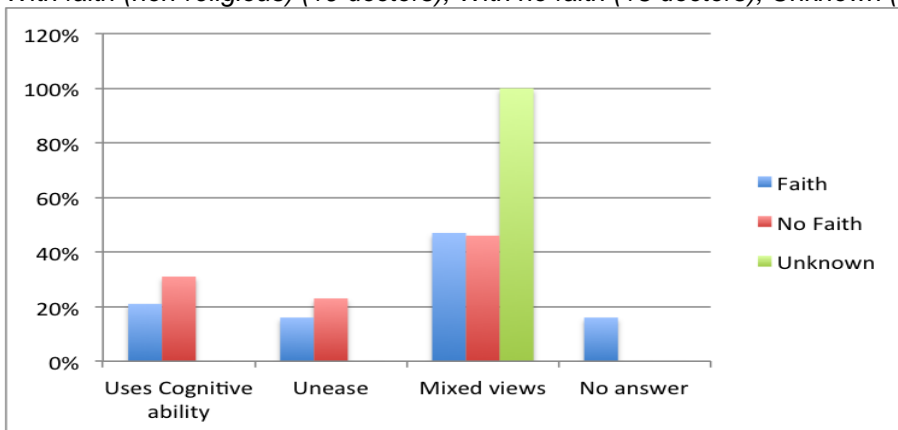
6.8. How do doctors with and without religious faith compare in their approaches to a child's cognitive ability?

The doctors' responses were also examined using the same methodology to explore whether there was any suggestion in the data that the religious doctors approach a child's cognitive ability differently from non-religious doctors. The doctors' responses suggest little difference in approach between religious doctors and non-religious doctors. Any differences found were small. Four religious doctors (21%) were positive about the use of a child's cognitive ability in these decisions, compared with four non-religious doctors (31%). In similar vein, three religious doctors (16%) expressed unease at its use compared with three non-religious doctors (23%). The percentage of doctors with and without faith who expressed a mixed view was even closer, with nine religious doctors (47%) doing so and six non-religious doctors (46%). The suggestion then from this data is that a doctor's faith does not seem to impact on the weight a doctor puts on a child's cognitive ability when making difficult decisions for a disabled

⁶⁶⁷ Chapter two, pp.23-94

child. However, once again there does seem to be a lack of consensus amongst the doctors in this study as a whole, as to what weight should be put on this factor.

Figure 56: Use of a child's cognitive ability and religious faith
 Presented as a percentage of doctors with and without religious faith (religious)
 With faith (non-religious) (19 doctors); With no faith (13 doctors); Unknown (1 doctor)



To summarise the findings on the use of a child's cognitive ability, the doctors' survey responses suggest a lack of consensus amongst doctors as to whether it should be used when making difficult decisions for disabled children. More neurologists indicated that they do use it than doctors from other sub-specialisms, but an equal number of neurologists also express their unease at its use. In contrast to quality of life, but in keeping with futility, 1990s qualifiers seem happier to use it in their decisions than their more experienced colleagues, parent doctors seem most inclined to object to its use.

7. Conclusions to be drawn about how doctors make difficult decisions for disabled children from what doctors in this study wrote about prognosis; futility; quality of life and a child's cognitive ability.

The overwhelming conclusion to be drawn from the data presented in this chapter is the diversity of views expressed by a pool of thirty-three paediatricians who, as was seen in chapter four,⁶⁶⁸ come from a relatively narrow spectrum of society and even of the medical profession. With every factor, the doctors showed diversity as to the weight they put on that factor and as to what should be considered when evaluating that factor. There is an indication in the data that certain personal and professional characteristics do potentially influence a doctor's approach to a factor, but there was inconsistency as to the impact of personal and professional characteristics across the factors considered.

1990s qualifiers when compared with earlier qualifiers, for example, seemed more inclined to use futility and a child's cognitive ability as a factor, but less inclined to use a child's quality of life, despite the seeming links between these three factors. Neurologists seem to stand out as approaching difficult decisions differently from PICU consultants and Other Doctors, and seem more inclined to use clinical factors than non-clinical factors in their decision-making. It is of interest that parent doctors seem to approach difficult decisions in some respects differently from relative doctors, suggesting that the *nature* of a doctor's personal experience of disability is important not just whether a doctor *has* personal experience of disability. There are indications that the hidden curriculum may not be as influential as might be expected, with possibly the changes in law discussed in chapter two, impacting more on 1990s qualifiers' decisions, than on the decisions of more experienced consultants, however, the data suggests this is not clear cut.

⁶⁶⁸ Chapter four, para four, pp.139-157

Quality of life as a factor stands out for the diversity of ways it is used by doctors, suggesting, more than the other factors, doctors use it as a proxy for a child's best interests, using it to draw upon a wide range of clinical and non-clinical or welfare factors.

When examined through the lens of the Kennedy Debate, the findings in this chapter suggest a mixed picture. In generational terms, doctors who qualified close to the start of the Kennedy Debate seem to, in general terms, be less inclined to use the non-clinical factors, Kennedy suggested doctors should not be assessing, than more recently qualified doctors. However, as was seen, quality of life as a factor seems to contradict this.

When examined through the lens of the jurisprudence of the English High Court and doctors' professional guidance, the findings in this chapter seem to suggest that the doctors in this study are inclined to explore best interests widely, especially the wider welfare issues, as they are guided. Indeed, the data seems to suggest the overall doctors put more weight on non-clinical than clinical factors when deciding for a disabled child. The potential conflict here with what Kennedy advocated has been highlighted. In the next chapter, the last in part two of this thesis, the question as to how doctors make these non-clinical assessments is considered as part of the discussion of what the doctors said at interview about uncertainty and disagreement.

Chapter Six

Uncertainty and Disagreement

1. Introduction

This chapter presents and discusses what the doctors said in their interviews about uncertainty and disagreement. In doing so this chapter answers the second part of research question one, namely what aspect of their difficult decisions the doctors found most difficult. It also expands on what was learnt in the last chapter about what factors the doctors used in their difficult decisions, in so doing, further answering research question two.

Uncertainty and disagreement are chosen for detailed analysis, as they were highlighted in the doctors' survey responses as being the most difficult aspects of these decisions. They were then both discussed by all the interviewed doctors in some detail, reinforcing the suggestion in the study survey responses that they are the two topics the doctors believed to be most pertinent to their best interest decisions for disabled children.

The interviews were semi-structured enabling each doctor to concentrate on the issues he or she thought most pertinent. Some of the doctors spoke at great length, the longest interview lasting over two hours, other doctors spoke for a shorter amount of time, the shortest interview lasting fifty minutes. The doctors also had different personalities, some being very outgoing and eager to talk, such as Drs 17, 10 and 32, with others seeming to be much quieter personalities, such as Drs.1 and 18. Some were very earnest, such as Drs 17 and 18, while others were much more relaxed, at times laughing and joking, such as Drs 10 and 29. All the doctors showed great interest in the subject being discussed, but for some it was clearly a topic of great interest, even passion. The doctors showed great eagerness to share their knowledge and insights on the topic at length. While some doctors talked more about their training and education, others talked more about law and ethics. Uncertainty and disagreements were, however, raised repeatedly by the doctors.

The main focus of this chapter is what was said by the nine doctors interviewed, but this chapter will also refer back to the responses from the surveyed pool of doctors, when this adds a wider perspective. This chapter starts with a table (figure 57), summarising the key characteristics of the interviewed doctors. It then considers uncertainty before moving on to disagreement. Three classes of uncertainty described by doctors: (i) diagnostic and prognostic; (ii) moral and (iii) roster uncertainty are first defined before each of these manifestations being considered in more detail. In their discussions of disagreements, rather than talking about different types of disagreement, the doctors instead talked about disagreements with different groups of people. For example, they talked about disagreements between sub-specialists; disagreements between doctors from different generations and disagreements between doctors and parents. The categories of disagreement identified by the doctors are therefore used as the basis for the discussion in this chapter of those disagreements.

As with the previous chapters, the existing lenses of the Kennedy Debate and best interest decision-making as defined by the English High Court and doctors' professional guidance are used in this analysis.

2. The interviewees

Figure 57: Doctors who were interviewed

Doctor	Sub-specialism	Gender	Age band	Decade qualified	Parent	Lived outside UK for 1 yr +	Trained outside UK	Worked outside UK	Ethnic Origin	Follows religion
1	Neurology	M	45-54	1980s	YES	YES	NO	NO	White British	YES
7	Neurology	M	55-64	1970s	YES	NO	NO	NO	White British	YES
10	Oncology	M	45-54	1980s	YES	YES	YES	YES	White British	YES
14	Respiratory	M	45-54	1980s	YES	NO	NO	NO	White British	NO
17	PICU	F	35-44	1990s	NO	YES	NO	NO	White British	NO
18	PICU	F	55-64	1980s	NO	YES	YES	YES	Asian	YES
24	Neurology	F	55-64	1970s	YES	YES	NO	NO	White British	YES
29	Neurology	M	65-74	1960s	YES	NO	NO	NO	White British	YES
32	Palliative Medicine	M	45-54	1980s	NO	NO	NO	NO	White British	YES

This page is intentionally blank

3. Defining Uncertainty

“Medicine is a very uncertain business and I think, well I suppose any time one prognosticates you are just setting yourself up for a fall because it is hugely uncertain. Even if there is a clear diagnosis and there is a well described natural history of a particular condition, every child is different.”

Dr 14

3.1 Dominance of uncertainty

Uncertainty featured prominently in the data in this study. For example, Dr 14 quoted above, spoke at great length about uncertainty and saw it as having considerable impact on not just doctors’ decision making, but also their careers. He suggested that some doctors coped better with uncertainty than others and that this influenced a doctor’s choice of sub-specialism. He said:

“I think there is a greater or lesser need for certainty I think one thing that strikes me,[is] that, there are some specialties where certainty almost doesn’t exist. There are a lot of difficulties in making precise diagnosis; the natural history of diseases. In other specialties it is very cut and thrust really, you need to make a quick diagnosis, quick treatment and get on with it and the outcome is either good or bad.”

The doctors not interviewed had also stressed the significance of uncertainty on their difficult decisions for disabled children in the survey. For example, Dr 9 (neurologist) wrote, *“we really have little accurate ability to predict long term outcome.”* Writing about futility, Dr 2 (PICU) wrote that it is a *“judgment and not clear cut”* and Dr 13 (Other) wrote it is *“difficult to assess.”* The doctors also wrote of the difficulty of assessing a child’s quality of life. For example, Dr 19 (neurologist) said it is *“notoriously difficult to get this right; most doctors tend to assume children are worse than they really are.”* Dr 28 (PICU) explained *“There are no validated tools [for] the ventilator dependent child. I get a community paediatrician to give an objective assessment, but they struggle.”*

3.2 What is diagnostic and prognostic uncertainty?

The doctors talked about diagnostic and prognostic uncertainty; the high level of uncertainty they and their colleagues face when making any assessment for

a severely disabled child. They discussed the great uncertainty in a child's diagnosis or prognosis and the difficulty they face in making, for example, an accurate assessment of a disabled child's cognitive ability or quality of life.

The doctors explained that diagnostic uncertainty might happen because a child had a very rare condition or because of huge variation in children with the same condition. However, the outcome for an individual child did not just depend on the child's diagnosis, prognosis, clinical presentation or indeed medical factors. They spoke of the importance a child's home environment and the support available to the child locally, could have. Another aspect of prognostic and diagnostic uncertainty, which troubled doctors, was the uncertainty as to what level of impairment was acceptable for a child; at what point did an impairment become too much for a child? In summary, the doctors suggested that there were often too many variables to be certain for an individual child.

3.3 What is moral uncertainty?

The second class of uncertainty the doctors raised is perhaps best described as a moral uncertainty; a lack of certainty as to whether they or their colleagues had made the right decision for a child, especially when that decision was to withhold or withdraw treatment. This moral uncertainty seemed to arise less if a decision had been made to treat a child as then all options were still open, which they clearly are not once a child has died. When treatment is withheld or withdrawn doctors seem to worry about the 'what ifs?'

The doctors seemed to vary in their approaches, some clearly struggling greatly with this moral uncertainty. The doctors who knew the children best tended to have more self-doubt, perhaps because they had an emotional attachment to the child, while the doctors who did not know the children well seem to express more confidence in their decisions.

3.4 What is roster uncertainty?

The third class of uncertainty described by the doctors was an uncertainty more for the children and their families than for the doctors. With this type of uncertainty, the doctors describe outcomes for the child, even whether a child lives or dies, being dependent not on factors related to the child, but rather the 'chance' of which doctor happened to treat the child. Wilkinson & Truog describe this phenomenon as the 'roster lottery'⁶⁶⁹ so perhaps roster uncertainty is a suitable name for it. This variation in treatment decisions based on doctors' professional and personal characteristics and values has also been identified by other researchers, as was discussed in chapter four.⁶⁷⁰ Wilkinson and Truog's paper⁶⁷¹ is, however, drawn upon particularly here, because their study is contemporaneous with the empirical research in this thesis, meaning that they were writing about the issue at the same point in time, as the doctors in this study were reflecting upon it. Wilkinson's writing about decision-making for neonates⁶⁷² is also chosen for discussion, as the comparison between the process of decision-making for infants and for older children, as has been seen,⁶⁷³ is an important one for this thesis. Wilkinson's discussion of neonates helps draw out the distinction this thesis makes.

The doctors in this study described how differences in values held by doctors towards severely disabled children, not just from one hospital to another, or between doctors with different sub-specialties, but between consultants from the same sub-specialism within the same unit, lead to differences in care and

⁶⁶⁹Wilkinson, D, Truog, RD, (2013) The luck of the draw: physician-related variability in end-of-life decision-making in intensive care, *Intensive Care Medicine*, 39, 1128-1132 at P.1128

⁶⁷⁰ Chapter four, para.4, pp.145-146

⁶⁷¹ Wilkinson, D, Truog, RD, (2013) The luck of the draw: physician-related variability in end-of-life decision-making in intensive care, *Intensive Care Medicine*, 39, 1128-1132

⁶⁷² Wilkinson D; (2013) *Death or Disability? The 'Carmentis Machine' and decision-making for critically ill children.* Oxford University Press, Oxford

⁶⁷³ Chapter five, para 5.3, pp.211-212

treatment and potentially to the difference between life or death for an individual child.

What the doctors said about uncertainty in each of these classes is now presented and then discussed.

4. **Prognostic and Diagnostic Uncertainty**

4.1 What the doctors said

Several of the doctors talked about the difficulty of predicting outcomes or assessing a child. When asked how easy it is to come to a prognosis for a severely disabled child Dr 1 (neurologist) replied:

“The short answer is not easy. There are some conditions you recognise are inherently progressive and obviously those are going to have a shorter life expectancy. There are others, which are not inherently progressive, but are life threatening. But you know that there are children who have particularly respiratory complications with neurological disease who are going to have shorter life expectancies, you know, but in general terms.”

Dr 14 (Other) went further in his answer to the same question:

“It can be frighteningly difficult in some of these cases...in many of these cases we don't have a diagnosis, a diagnosis is never made and therefore the prognosis is completely unknown and there are anecdotal cases where children have looked hopeless in the first few months of life and then have made fantastic strides and then, like a patient of mine, who I can just bring to mind, who by the age of five, was doing ballet dancing and things, but at the time looked just like children I have seen who had a hopeless prognosis and would have died.”

Likewise, PICU consultants spoke of the difficulty of knowing which patients would benefit from intensive treatment. Dr 18, for example, talking about predicting the outcome of intensive care said:

“It is not easy, it is not easy at all”

Another PICU consultant, Dr 17 also talked of uncertainty when a decision is made to withdraw treatment:

“Now it is very difficult to be a 100% certain and when you withdraw intensive therapy it is not always a self-fulfilling prophecy. I have children survive withdrawal of intensive therapy, you always have to parallel plan for palliative therapy on going. The longest survivor I’ve got of withdrawal of intensive therapy is 18 months.”

The doctors also talked about uncertainty when assessing a child’s quality of life or cognitive ability; the second of these factors being, some of the doctors suggested, intrinsic to a worthwhile quality of life. As was seen in the chapter five,⁶⁷⁴ doctors making assessments as to a child’s quality of life or cognitive ability is far from controversial, with a lack of consensus between doctors as to whether these are factors should be assessed or the weight to be put on each of these factors and in the case of quality of life, what it even means. However, as was also seen, doctors do make these assessments. As such, the doctors can be said to be making a prognosis as to a child’s quality of life or cognitive ability and so these assessments are included within this discussion.

Talking of assessing a child’s quality of life, Dr14 (Other) said:

“I just think that we are absolutely hopeless at judging the quality of life of people with disabilities and I suppose having insight and cognisance of that, is in some ways reassuring, but it makes the judgment more difficult.”

Dr 7 (neurologist) expressed the opinion, echoing the findings of Martin et al’s⁶⁷⁵ discussed in chapter two,⁶⁷⁶ that doctors can under estimate the ability of children with severe physical impairment to understand, conflating, wrongly in his view, a physical inability to communicate with severe cognitive impairment, while acknowledging the uncertainty of assessing a child’s abilities. He said:

“for children with cerebral palsy you can fall into the trap of underestimating their ability because of their lack of ability to

⁶⁷⁴ Chapter five, pp. 182-236

⁶⁷⁵ Martin, HI, Rowell, MM, Reid, SM, Marks, MK, Reddihough, (2005) Cerebral palsy: What do medical students know and believe? *J. Paediatric Child Health*, 41, 43-47

⁶⁷⁶ Chapter two, para 10, p.88

communicate... but in some children you look at the scan showing widespread brain injury and you look at any level of response which is pretty minimal and you can always raise the argument, are there pockets of huge ability locked in, but in life sometimes you have to say, you can never be sure about anything in biological terms” Dr 7

A concern that his colleagues could underestimate the abilities of severely disabled children was also one expressed by Dr 32 (Other). Indeed, with both Drs 7 (neurologist) and 32 (Other) there was a sense in their remarks that some of their colleagues were, in their view, being too certain about some things, rather than recognising factors as being uncertain:

“I do think there is a sense that people who do not know children who are cognitively delayed will often assume that they are not engaged with their environment, that they cannot enter relationships. It is of course extremely rare for even the most profoundly impaired child not to be able to participate in relationships, not to be able to do most of those things.” Dr 32

4.2 Discussion

Uncertainty is inherent in medicine. In the words of Donald Irvine, a former president of the GMC:

Many people outside the profession do not appreciate that medicine is not an exact science. In fact, it is prone to error and inherently risky.⁶⁷⁷

A doctor’s opinion concerns:

‘what will happen in the future, often we cannot know with certainty, or indeed with any real degree of assurance, the outcome of each choice we might make.’⁶⁷⁸

The extent to which doctors struggle with uncertainty can be seen in research conducted by Lantos and Meadows⁶⁷⁹ in a neonatal intensive care unit in the USA. It assessed the ability of staff to identify infants who would survive to

⁶⁷⁷ Irvine, DH, (2007) Everyone’s Entitled to A Good Doctor, *Med J Aust*, vol. 186; no.5, 256-261, at p.258

⁶⁷⁸ Nuffield Council (2006) *Critical Care Decisions in fetal and neonatal medicine: ethical issues*. Nuffield Council on Bioethics, London, at para 2.25, p.16

⁶⁷⁹ Lantos, JD, Meadows, W (2006) *Neonatal Bioethics: the moral challenges of medical innovation*, The Johns Hopkins University Press, Baltimore, pp. 95-96

leave the unit and those who would not. The study lasted 18 months and involved 333 infants. They report:

‘of the babies who were so sick that on at least one day every single doctor and nurse predicted that the infant would die, almost one-quarter of these babies still lived to be discharged’.⁶⁸⁰

The authors concluded:

‘Neither objective, quantifiable measures of illness severity nor institutive qualitative assessment by experienced clinicians can eliminate the gray [sic] zone of clinical uncertainty. Both prognostic approaches appear best at anticipating impending death only when accuracy does not matter much – for doomed infants with the worse physiology, who will die soon anyway.’⁶⁸¹

For severely disabled infants, Wilkinson, an ethicists and neonatologist, suggests that uncertainty is all the more prevalent because:

‘Apart from variation in physical susceptibility and recovery from injury there are also differences in psychological susceptibility in the ability of individuals to adjust and cope with adversity. Different children have different degrees of resilience to injury and illness’⁶⁸²

Wilkinson argues that two infants can have very similar neurological injuries, but the outcome for the two can be very different depending on a broad spectrum of factors, including the child’s genetic make-up; family and society support and the child and his or her family’s resilience,⁶⁸³ a view echoed by doctors in this study.

While, the doctors describe, uncertainty as to prognosis and diagnosis as inherent in the care of many severely disabled children, there is the argument made earlier,⁶⁸⁴ that once a child progresses beyond infancy, in many respects,

⁶⁸⁰ Ibid

⁶⁸¹ Ibid

⁶⁸² Wilkinson, D (2013) *Death or Disability? The ‘Carmentis Machine’ and decision-making for critically ill children*, Oxford University Press, p. 163

⁶⁸³ Ibid pp 163-164

⁶⁸⁴ Chapter five, para 5.3, pp. 211-212

assessments should be less uncertain than for infants. As Wilkinson identifies infants are much harder to assess neurologically because:

their limited repertoire of skills means that neurological assessment is necessarily more broad-brush and more uncertain.⁶⁸⁵

In comparison, much more should be known about older children with neurological impairments. They have an identifiable history, in some cases of more than a decade, and not just a medical history, but also a social and educational one. They are known to many more people: wider family, health professionals and wider professionals.⁶⁸⁶ A child's likes and dislikes will be known, as will, very likely, how he or she reacts to medical procedures and copes with his or her impairment. For an older child, it is much more likely that a clear pattern of health will be established. It should be known, for example, whether the child is one who becomes acutely unwell, but copes with treatment well and recovers well, or whether a child is becoming more and more unwell and the burdens of any treatment are outweighing the benefits. Some older and more cognitively able children will be able to express an opinion on treatment decisions, including end-of-life decisions. Even younger and less cognitively able children may, as previously suggested, have communicated preferences through their reactions to past episodes of acute illness and treatment. As Dr 32⁶⁸⁷ suggested, it is extremely rare for a child not to be able to interact at all. In short, far more will be known about the child, by a much wider group of people. This seemingly makes the task of exploring the child's best interests 'in the widest sense,'⁶⁸⁸ much easier, as so much more is known about the child. This brings to the fore one of the reasons why it is important to know how, in the

⁶⁸⁵ Wilkinson, D (2013) *Death or Disability? The 'Carmen Machine' and decision-making for critically ill children*, Oxford University Press, p.166

⁶⁸⁶ The voluntary organisation Together For Short Lives lists some of the people likely to be involved in a child's life

http://www.togetherforshortlives.org.uk/assets/0000/1704/Who_s_who.pdf accessed 16 August 2017

⁶⁸⁷ Chapter six, para 4, p. 246

⁶⁸⁸ *Re OT* [2009] EWHC 633 (Fam), per Parker J

context of this thesis, doctors make best interest decisions for disabled children, because it allows for an assessment to be made as to whether doctors are consulting widely on these issues, as they are guided to do by their professional guidance and the jurisprudence of the English High Court.

A concern raised by doctors in this study who work with the children long term, was that despite this information being known, some of their 'acute' colleagues, rather than balancing the benefits and burdens of any treatment to the individual child based on this information, fall back on heuristics.⁶⁸⁹

What this means will be briefly explained.

Heuristics, as Brush⁶⁹⁰ explains, are used by doctors to 'simplify difficult decisions' and to 'avoid analysis paralysis' under conditions of uncertainty that demand speed.⁶⁹¹ However, problems can arise if a doctor uses a heuristic 'fast and frugal rule of thumb'⁶⁹² rather than carries out a more detailed best interest assessment. The main criticism of heuristics in the context of the decisions under discussion in this thesis, is that they do not seem to distinguish between different children who superficially may seem similar. For example, many children have severe cognitive or physical impairment, but may need very different treatment to meet their individual best interests. In the words of Dr 18 (PICU) talking about colleagues who use rules or heuristics when deciding who to treat:

"You can't have 'in this scenario do this and in that scenario do that', because every patient has a completely different scenario and for one patient it might be the right thing to do and for another patient it might not."

⁶⁸⁹ Brush, EJ, (2015) Decision-Making shortcuts: the Good and the Bad, *New England Medical Journal*, Massachusetts, www.knowledgeplus.nejm.org accessed 15 July 2016

⁶⁹⁰ Ibid, para 2

⁶⁹¹ Ibid, para 2

⁶⁹² Ibid, para 2

Doctors use heuristics because they 'often have to make rapid decisions, either because of a medical emergency or because they need to see many patients in a limited time,'⁶⁹³ but their use in potential end-of-life decisions it seems from the doctors' accounts, is too simplistic and sometimes does not pay sufficient attention to the individual circumstances of the patient. Klein⁶⁹⁴ identifies several pitfalls of heuristics in medical decision-making among them 'the representative heuristic', that is, 'the assumption that something that seems similar to other things in a certain category is itself a member of that category'.⁶⁹⁵ Dr.17(PICU) used a rule that a child can only have one admission to PICU. It can be argued that Dr 17 is putting all disabled children who have had a previous admission to PICU in the same category, of children for whom it is not in their best interests to have PICU treatment. However, there is a significant difference between a child who has had repeated recent admissions to PICU and a child who had one earlier admission to PICU, perhaps a decade ago. Although speaking at great length, Dr 17 did not suggest that she would make these kinds of distinctions, but instead suggested she would rely on the heuristics she had devised to guide her decision-making. Being a PICU specialist, as has been previously discussed,⁶⁹⁶ Dr 17 is unlikely to know a child prior to considering whether to admit him or her to PICU or to have an in-depth knowledge of the child's medical or social history. In these circumstances, it is perhaps not surprising that the Dr 17 had developed a series of heuristic markers to guide her decisions. This is all the more so when dealing with a child whose symptoms suggest urgent action is needed.

However, heuristic markers are arguably far too crude and blunt instruments, particularly when the outcome of the decision will determine whether the child

⁶⁹³ Klein, JG, (2005) Five pitfalls in decisions about diagnosis and prescribing, *BMJ*, 330: 781-784, p. 781

⁶⁹⁴ Klein, JG, (2005) Five pitfalls in decisions about diagnosis and prescribing, *BMJ*, 330: 781-784

⁶⁹⁵ *Ibid*, p.781

⁶⁹⁶ Chapter five, para 2, p.183

lives or dies. The use of heuristic markers also seems to be a long way removed from how doctors are guided to make best interest decisions by their professional bodies and the English Court. Relevant information about a child can also be overlooked and 'physicians can be insensitive to the reliability of information, or to the degree to which information allows an accurate judgment to be made and over-weight low-relevance diagnostic information'⁶⁹⁷ as some of the doctors seem to suggest they do in this study.

The relevance of doctors using heuristics, especially about non-clinical factors, to the Kennedy Debate is clear.

Using heuristics can mean the best interests of the individual child are not always examined. It does seem that the doctors who use heuristics do so to overcome uncertainty and gaps in their knowledge about the individual child. Some doctors in this study (for example Drs 24 and 14), did express concerns that treatment is being withdrawn or withheld from disabled children inappropriately. It seems that one significant reason as to why this is happening, may be that doctors are addressing uncertainty by adopting heuristics rather than seeking out information (which, in the case of a child beyond infancy, is likely to be available) that is needed to make an informed decision, as their professional guidance guides them to do.

5. Moral Uncertainty

5.1 What the doctors said

The second type of uncertainty several of the doctors describe is moral uncertainty, namely, an uncertainty as to whether the doctor did or even routinely does the right thing. This manifested itself in two forms. Firstly, doctors express uncertainty as to whether they themselves made the correct decision for a child, usually a decision to withdraw or withhold

⁶⁹⁷ Brush, EJ, (2015) Decision-Making shortcuts: the Good and the Bad, *New England Medical Journal*, Massachusetts, www.knowledgeplus.nejm.org accessed 15 July 2016, para 11

treatment. Secondly, moral uncertainty is expressed as to whether a doctor was correct not to challenge a colleague who held a different view as to a child's best interests, especially if the doctor experiencing the uncertainty knew the child better than the doctor making the decision. Although not something that can easily be conveyed here, moral uncertainty was often expressed by doctors in how they spoke, often speaking much more hesitantly than in the rest of their interviews.⁶⁹⁸ When doctors talked about their uncertainty in this context, they often spoken more slowly, more quietly and with lots of pauses, while they seemed to reflect. This contrasted with how many of the doctors spoke in other parts of their interviews, which was often in a very animated fashion, quite fast and quite loudly, often conveying confidence in their opinions, and excitement at discussing the subject matter.

Dr 29 (neurologist) seemed to express the first of these manifestations of moral uncertainty when talking about trying to decide whether to ventilate or resuscitate a child:

"I really don't know what to do. My inclination would have been to give everybody the benefit of every doubt, but in the end, to see it as being a method of departing life as well.

You see somebody who has plainly suffered a major piece of brain damage, you can't sort of remove that, er my guess is you resuscitate them anyway, because you don't precisely know the form of the and they will have some sort of life and I suppose you have to give them that opportunity."

Dr 14 (Other) expressed similar moral uncertainty as to the point at which treatment should be withheld or withdrawn:

"I suppose this is the difficulty really, isn't it, whether one has some line on the support one would give in that situation"

He went on to vividly describe the impact this moral uncertainty has on him:

"I lie awake at night thinking that I have consigned a child to death and I do not know if that is the right decision.

We have to make a decision for what is right and what is wrong for individual patients, a whole variety of things, I think you can, you can get

⁶⁹⁸ When doctors used 'ems' and 'ers' while speaking, these have been left in their quotes.

lost in the maze of the philosophical and the moral arguments and lose the ability to make decisions.”

Talking of some decisions made to withdraw treatment Dr 14 concluded:

“You think, I’m, not sure we did the right thing there, em, but we will never know”

Dr 24 (Neurologist) expressed her moral uncertainty with the question:

“Are we doing too much?”

In contrast Dr 17 (PICU) addressed her uncertainty by ‘doing it all’:

“Often we will go into ITU not knowing if it is going to be useful. If I am in a situation where I don’t know I would rather do it all and stop it all later.”

5.2 Discussion

It seems clear from their comments and also their manner and tone when making those comments, that some of the doctors encounter huge moral uncertainty when making difficult decisions for disabled children. As Wilkinson & Truog identify, decisions whether to limit or continue life support in all critically ill patients can be ‘highly value-laden and contentious’.⁶⁹⁹ This is likely to be all the more so when the patient is a child and, as research has found, has an even greater emotional impact on the doctor.⁷⁰⁰ Indeed, the doctors who expressed moral uncertainty in this study tended to be doctors who had long-term relationships with the child. Some of the doctors had worked with particular children over many years and formed close relations with them. This is recognised in the current version of the RCPCH’s guidance for doctors on making decisions to limit treatment, (‘RCPCH 2015’) which states:

⁶⁹⁹ Wilkinson, D, Truog, RD, (2013) The luck of the draw: physician-related variability in end-of-life decision-making in intensive care, *Intensive Care Medicine*, 39, 1128-1132, p.1128

⁷⁰⁰ For example, Smith, Hamilton, S, Grimard, L J (2014) The emotional and psychological impact on radiation therapists of treating children. *Journal of Medical Imaging and Radiation Sciences*, 45(3), 276-282 found 81% of radiotherapists in their study reported treating children caused higher anxiety than treating adults.

‘the fact that some members of the team may have difficulties ‘letting go’ should be acknowledged and addressed’⁷⁰¹

The guidance does not, however, explain how this should be addressed.

Dr 18 (PICU) suggested that the outcome, particularly for a disabled child “*very frequently*” depends on “*how assertive the referring doctor, [or] how assertive the parents are.*” Despite this, doctors suggested that they often did not speak up if they disagreed with colleagues’ decisions. It seems then that best interest decisions for disabled children are not always as wide ranging as they should be, at times because some doctors are reluctant to offer information they know about the child, despite believing it to be relevant.

The doctors’ observations suggest they face a choice between respect for their colleagues’ autonomy of clinical judgment on the one hand and their duty to act in a child’s best interests on the other. The doctors suggest, first, that this is not an unusual dilemma for them when the best interests of a disabled child are being evaluated; and secondly that they will often seemingly prioritise a colleague’s autonomy of clinical judgment over a disabled child’s best interests. There is a suggestion from the doctors in this study of a hierarchy of consultants, with PICU consultants often placed at the top of that hierarchy, the ultra-elites described in chapter three.⁷⁰² Dr 14 (Other) illustrated the sentiments expressed by several of the doctors who expressed moral uncertainty in their answers when he spoke of a fear of “*rocking the boat*” and it being easier to “*just go with the flow.*” Doctors talked of a deep-rooted culture of respect for colleagues ingrained in them since medical school. This chimes with the statements of Irvine, who talks of the same ‘intrinsic self-protective nature of medical culture’⁷⁰³ where he said ‘Turning a Nelsonian blind eye was

⁷⁰¹ Larcher, V, Craig, F., Bhogal, K, Wilkinson, D, & Brierley, J (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice, *Archives of disease in childhood*, 100 (Suppl 2), para 3.3.1. s 17

⁷⁰² Chapter three, para 2.2, pp. 99-100

⁷⁰³ Irvine, DH, (2007) Everyone’s Entitled to A Good Doctor, *Med J Aust*, vol. 186; no.5, 256-261, p. 257

the easiest thing to do'.⁷⁰⁴ However, Irvine suggests this culture died out following the Bristol,⁷⁰⁵ cited in chapter two,⁷⁰⁶ which he says shocked the medical profession.⁸⁷³ Bristol was undoubtedly a catalyst for changes in the professional regulation of doctors, as Irvine describes,⁷⁰⁷ however, comments from the doctors in this study, all but one, senior paediatric consultants, suggest that the changes Irvine describes were not universal. Several of the doctors suggest they do turn a blind eye, rather than rock the boat. It is noteworthy that at the time of Bristol and the changes it led to, the majority of consultants in this study would have been well established in their careers. They are the doctors who lead on difficult decisions for disabled children at present. What is not clear is the extent to which there has been a culture shift in the attitudes and behaviour of doctors who have qualified post Bristol in terms of speaking up if they disagree with a colleague. This is a question that merits further research.⁷⁰⁸

Once again, there appears to be a gap between what doctors according to their professional ethical guidance and the law, should be doing, and what they report happens day-to-day in practice. The doctors suggest that best interest decisions are not always wide-ranging decisions, involving all parties, as they should be. In part, the doctors suggest, this is because of a reluctance on the part of doctors to share their opinions. It does seem that if decisions were being made as guided, moral uncertainty, like prognostic and dynastic uncertainty, could potentially also more easily be addressed.

⁷⁰⁴ Ibid

⁷⁰⁵ The Bristol Royal Infirmary Inquiry (2001), *The Inquiry into the management of care of children receiving complex heart surgery at the Bristol Royal Infirmary, Final Report*, Bristol Royal Infirmary Inquiry

⁷⁰⁶ Chapter two, para 8, pp.75-76

⁷⁰⁷ Irvine, DH, (2007) Everyone's Entitled to A Good Doctor, *Med J Aust*, vol. 186; no.5, 256-261, pp.257-261

⁷⁰⁸ See chapter ten, para 5.1.1, p.399

When the doctors talked about their moral uncertainty, their comments suggested that it caused them real distress. Some doctors appear to avoid this distress by using heuristics, discussed earlier, which seem to distance doctors from their decisions, in part perhaps because they appear to treat children as ‘types’ and avoid dealing with them as individuals.

Unfortunately, however, in doing so, they seemed to be adding to their other colleagues’ distress, as those colleagues appear to suffer moral uncertainty over their failure to challenge the decisions of the doctors using heuristics.

Moral uncertainty may not, however, be all bad from the child’s perspective. A doctor experiencing some moral uncertainty could be positive, if it encourages the doctor to stop, think and more actively consider the individual child’s best interests. However, as Fox⁷⁰⁹ identifies, too much moral uncertainty acts as a barrier to doctors making decisions, leading to ‘paralysis analysis,⁷¹⁰(an inability to make any decision), if they experience decision-making as overwhelming. It can also, it seems, encourage the use of heuristics, rather than a detailed analysis of an individual child’s best interests.

6 Roster Uncertainty

6.1 What the doctors said

Dr 14 (Other) talked about the “*Russian Roulette*” of care for severely disabled children. He refers to a sense some doctors had that whether a child lived or died was uncertain, not because of factors relating to the child, but rather factors relating to the doctor treating the child. Dr 14 went as far to say that whether an individual disabled child lived or died could depend not on the child’s condition, but on what day of the week the child arrived at hospital, which

⁷⁰⁹ Fox, CR (2010) ‘Medical Uncertainty Revisited’ in Albrecht, GL, Fitzpatrick, R, Scrimshaw, SC, (Eds), *Handbook of Social Studies in Health and Medicine*, Sage Publications, Thousand Oaks

⁷¹⁰ Brush, EJ, (2015) Decision-Making shortcuts: the Good and the Bad, *New England Medical Journal*, Massachusetts, www.knowledgeplus.nejm.org accessed 15 July 2016, para 2

would dictate which doctors, treated the child and so the treatment the child received:

“I can think of the combinations of doctors that, let’s say intensive care doctors, neurology doctors and respiratory doctors, I can think of combinations of those that would make a decision go one way or another. So what I worry about is equity and that it just so happens that if you pitch up on a Wednesday in May you get this particular combination, if you pitch up on a Thursday in April you get a different combination and that will determine your outcome.”

He went on to say:

“I think doctors are very conscious of the fact that there is a huge variation in medical opinion about everything. If you put 12 respiratory physicians together you get 12 different answers, we are talking about critical decisions which may mean life or death. Any decision you get a huge variance of opinion and everybody in medicine is fully cognisant of that and I suppose it comes down to what is a reasonable body of opinion and er, present opinion might be a reasonable body, but I think, er, it is almost you can’t just have it as a poll, the majority wins, because that still might not be right and I think what is right for the patient is a very intangible quality really, difficult to pin it down to something that can, can have certainty, because it has always got an element of uncertainty.”

Other doctors also raised this variation in approach leading to different outcomes for a child. The two PICU specialists interviewed spoke of how their own practice varied from that of their PICU colleagues.

Dr 17 (PICU) explained:

“We all have a slightly different line that we, em believe is the time to stop intensive therapy, we are not all completely the same. Myself and one of my colleagues are known to be the doctors who will withdraw intensive therapy the most frequently, the most actively.”

Dr 18 (PICU) also spoke of the impact of different doctors’ approaches for a child’s outcome. She started by saying that she thought a doctor’s religious beliefs were a factor, but qualified this saying:

“I suppose it is not so much religion, but how aggressive some intensivists can be in not offering treatment. Even in how they talk to parents they can project a very negative view, or a slightly more positive hopeful view and I have had some colleagues saying that I have changed treatment and the difficulties is not black and white, say if you,

the patient was awful and they felt that the patient shouldn't be treated, but if things change and things improve, then you can't stick to a DNR order just because that was decided by a colleague two days ago. Also, how you say something, you can create a negative or a positive spin and some parents have said some people can be very, very negative and can almost condemn the child to no recovery and an awful prognosis."

Doctors suggested that they tended to take very individual approaches based on their values, rather than the child's clinical presentation, echoing the findings of chapter five.⁷¹¹

6.2 Discussion

In line with the views of the doctors in this study, others have also identified this seemingly random variation in care depending on the doctors treating a patient. As discussed earlier, Wilkinson and Truog⁷¹² refer to it as the 'roster lottery' saying 'This variability implies that how a patient's death is managed and even potentially whether or not they die, is influenced by which physician happens to be on call.'⁷¹³

In light of what doctors said about how they make difficult decisions for disabled children in their survey responses, especially the great variation seen between doctors, it is perhaps not altogether surprising that the outcome for an individual child can vary greatly depending on which doctor or doctors are making treatment decisions. As discussed in chapter two⁷¹⁴ larger studies⁷¹⁵ have also

⁷¹¹ Chapter five, pp.181-236

⁷¹² Wilkinson, D, Truog, RD, (2013) The luck of the draw: physician-related variability in end-of-life decision-making in intensive care, *Intensive Care Medicine*, 39, 1128-1132

⁷¹³ Ibid p.1129

⁷¹⁴ Chapter four, para. 4, pp.145-146

⁷¹⁵ See for example: Cuttini, M, Nadai, M, Kaminski, M, Hansen, G, de Leeuw, Lenoir, S, Persson, J, et al (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries, *The Lancet* 355.9221: 2112-2118; Richter, J, Eisemann, M, Zgonnikova, E, (2001) Doctors' authoritarianism in end-of-life treatment decisions. A comparison between Russia, Sweden and Germany. *Journal of Medical Ethics*, 27(3), 186-191 & Mebane, EW, Oman, RF, Kroonen, LT, Goldstein,

found that factors such as a doctor's gender, age, religion, sub-specialism, personal experience of disability and duration of practice all potentially influenced how a doctor approached best interest decisions for disabled patients.

It was also seen in chapter two⁷¹⁶ that findings from studies into health professionals' attitudes towards disabled patients suggest that decisions made for disabled people by doctors can be misinformed, and based on generalised prejudicial assumptions. Rather than informed decisions being made based on the individual's circumstances: 'ill-informed social judgments about disability' are substituted for 'medical ones'.⁷¹⁷ Doctors in this study who work closely with disabled children long-term expressed similar concerns. Wilkinson and Truog suggest that 'physician-related variability may be most prevalent when the patient's values were not known'.⁷¹⁸ Indeed, rather than drawing on known information about a child, assumptions about that child can be made. If, as research suggests, it is not unusual for doctors to have negative attitudes towards disabled patients, roster uncertainty creates a particular risk for the children in this study. Doctors in this study were clearly concerned by this roster uncertainty. Wilkinson and Truog also describe it as 'ethically problematic'⁷¹⁹ To be clear, the concern arises because the different opinions seem to emerge due to doctors' drawing on personal values, such as religious values or presumptions about the quality of a disabled child's life, rather than

MK (1999) The Influence of Physician Race, Age, and Gender on Physician Attitudes Toward Advance Care Directives and Preferences for End-Of-Life Decision-Making, *Journal of the American Geriatrics Society*, 47(5), 579-591

⁷¹⁶ Chapter two, para 10, pp. 82-91

⁷¹⁷ Basnett, I, (2001) 'Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467, p.455

⁷¹⁸ Wilkinson, D, Truog, RD, (2013) The luck of the draw: physician-related variability in end-of-life decision-making in intensive care, *Intensive Care Medicine*, 39, 1128-1132, p.1129

⁷¹⁹ Ibid, p. 1128

their clinical assessments of the patient. A doctor's values may be very different from those of the patient or his or her family. As Wilkinson and Truog conclude:

'The ethically relevant factors for these decisions include the best interests of the patients, the patient's preferences and values and potentially those of their surrogates, available resources and the prevailing law, but not the identity of the doctor'⁷²⁰

There seems to be agreement between many of the doctors in this study and the authors of the wider studies referenced here, that doctors should not bring their personal values to these decisions. It would also seem to chime with the concern expressed in the Kennedy Debate and contradict the doctors' professional guidance.⁷²¹ However, there also seems to be agreement that this is what commonly happens. To an extent, however, it is perhaps inevitable that doctors will bring their personal values to their decisions. Indeed, it is possible that doctors draw on their personal values to help cope with the moral uncertainty discussed in the previous paragraph, meaning that roster uncertainty is possibly in part an inevitable consequence of moral uncertainty.

While, there may be an element of inevitability in roster uncertainty, it is still ethically troubling and if, individual doctors are, for example, acting in ways which breach equality legislation, legally troubling as well. However, it does seem that if best interest decisions were made as doctors are guided to do by their professional ethical guidance and the law, many of the problems inherent in roster uncertainty, could to a large extent be overcome. If a full team of professionals who know the child rather than an individual or small team of doctors, together with the child's parents and where appropriate the child him or herself, are able to fully contribute to a best interest discussion, it seems there is less chance that the values of one or two members of that team will dominate the decision. Even more importantly, as Wilkinson and Truog suggest, when it comes to values, it is the values of the child (when these are ascertainable) or

⁷²⁰ Ibid, p.1129

⁷²¹ Chapter four, para 3, pp.142-145

his or her family, that should dominate the discussion, not that of the doctor. Indeed, doctors are told, by the GMC, as was seen at the start of the last chapter, to ensure they take into consideration of values of the family when making best interest decisions.⁷²² Doctors in this study however, suggest that it is the values of a doctor that can sometimes influence the outcome instead.

This topic will be returned to in the final chapter of this thesis, when consideration will be given to whether changes in law or procedure are need to help address this issue.⁷²³

Having presented and analysed what doctors said in their interviews about uncertainty this chapter will now turn to the closely related topic of disagreements that arise when making difficult decisions for disabled children.

7. Nature of Disagreements

The doctors talked a lot about disagreements in both their surveys and their interviews. In the survey, twenty-six doctors (78%) reported experiencing disagreements with other doctors as to an individual child's best interests and nineteen (57%) reported similar disagreements with a child's parents. The doctors talked about disagreements between doctors from different sub-specialists, most notably (but not exclusively) between PICU specialists and doctors from sub-specialties who tend to have long term working relationships with a child and his or her parents, such as neurologists. The PICU specialists also talked about disagreements amongst PICU consultants. Disagreements between doctors from different generations were also raised, as were disagreements between doctors and parents.

The rest of this chapter will now explore first, what doctors said about disagreements with other doctors, and secondly, what they said about

⁷²² See figure 11, p.138

⁷²³ Chapter ten, para 5.2, pp. 400-402

disagreements between doctors and parents. In each case, what the doctors said will first be presented, followed by an analysis of those discussions.

7.1 What the doctors said

7.1.1 Disagreements between sub-specialities

Dr 14 (Other) talked of “*polar differences*” between doctors from different sub-specialities. He explained some of the differences in approach of sub-specialities commonly involved in these difficult decisions:

“So the triumvirate that are often involved in decisions are neurologists, intensive care doctors and respiratory doctors and of course they are going to come at the cases from slightly different perspectives. We also have core differences in the way we approach things. Intensive care doctors like to sort things out and get them moving through. Neurology doctors tend to take a much longer-term view and possibly have a more optimistic outlook and we find ourselves somewhere in the middle.”

Dr 32 (Other) also identified differences in approaches between different paediatric sub-specialities. He suggested the disagreements often arose between doctors who know the children well and so, in his view, wanted to offer appropriate treatment and those who do not know the children and wanted to offer less:

“So I am thinking of intensive, neo-natal intensive care people, people who see the children when they are very sick and don’t get to know them as people and people who spend a lot of time getting to know those families and children; I’m thinking of palliative care and community paediatricians, perhaps general paediatrics and think what you find is that the people who get to know children, regard them as being, regard it as being more important to offer them appropriate treatment.”

PICU consultants were criticised by several doctors for their attitudes towards disabled children. Doctors gave examples, unprompted, of situations where they believed a PICU consultant had made an inappropriate judgment to withhold or withdraw treatment from a disabled child. All the neurologists interviewed were critical of PICU consultants. Dr 29, for example, talked of PICU consultants “*wish to move neurology patients on in a way that is not always appropriate*”, echoing what Dr 14 (Respiratory consultant) had said. Dr

29 confirmed when asked to clarify what he meant by “move on” that he meant the withdrawal of life-sustaining treatment. Dr 1 (neurologist) also spoke of PICU consultants pressuring colleagues to get parents to agree to withdraw or withhold treatment from disabled children. Dr 24 talked of “*prejudicial assumptions*” she had met from PICU consultants. She spoke of PICU consultants assuming that disabled children must have poor quality of lives and so should not receive PICU care. She gave an example of a PICU consultant refusing disabled children intensive care based on a mistaken belief that they did not attend school. Dr 32 (Other) also suggested that PICU consultants did not see disabled children as people:

“The problem is of course, that almost by their nature, intensivists, when they [see a disabled child] see just physical molecules if you like, they do not see any of the metaphysical person really, if I can call it that. It is not their fault, you know the child is unconscious when they are seeing them. I think it is difficult and I think, it is very inappropriate for intensivist to see themselves as gatekeepers for that reason”

Doctors complained of PICU consultants seeing themselves as the ‘*gate keepers*’ of NHS resources. Dr 24 for example, spoke of being told: “*I don’t think I can give her a resource*” in relation to a disabled child she believed needed PICU treatment. Dr 32 (Palliative Consultant) summed up a viewpoint, expressed by others;

“I think there is misunderstanding with physicians particularly those in intensive care, that they are supposed to be gate keepers for the state to an extent. That is in my view absolutely ethically unjustifiable.”

Several doctors spoke of having to advocate on behalf of disabled children with PICU consultants to get children treatment the doctors thought were in the child’s best interests. Dr 24 (neurologist) for example, spoke “*pleading with the intensivists.*”

Dr 18 (PICU), although a PICU specialist herself, also shared many of the concerns expressed about PICU consultants. She spoke of the fear and dread she saw in non-PICU colleagues when dealing with PICU colleagues reluctant to treat disabled children.

As well as criticising PICU consultants' values, doctors also criticised PICU consultants for failing to properly assess disabled children. Although they did not use the term, they appeared to be complaining about PICU consultants' use of heuristics.⁸⁹⁴ Dr 29 (neurologist) said:

“You often find that they have made a mistake, quite honestly and they have grouped the whole set of things together and produced a single score and what they haven't done is looked at the child's islands of development which means that they have got potential.”

As was seen earlier,⁷²⁴ doctors described a hierarchy of consultants, with PICU consultants viewed by non-PICU doctors as being 'in charge' when difficult decisions were being made. The doctors identified differences in values as the source of these disagreements. Dr 14 summed up the view saying:

“I think it is not so much medical, I think it is more down to belief systems and what one values. It comes down to one's personal morality, that will come from our cultural background, one religious background and just what makes us really.”

The two PICU consultants interviewed perhaps best illustrate these differences in values. As senior PICU consultants they worked with similar patient groups in a similar working environment, but expressed contrasting views.

Disagreements among PICU consultants are now explored.

7.1.2 Disagreements amongst PICU consultants

Dr 17 and Dr 18, the two PICU consultants, spoke about disagreements they had with their respective PICU colleagues.

Dr 17 described how she and other PICU consultants, who shared her values, restricted severely disabled children's access to PICU. She described in essence, using heuristics, making decisions based on a *type* of child. For example, Dr 17 described how she created her own tests to decide admission, such as whether a child could perform a particular physical task or had been to

⁷²⁴ Chapter six, para 5.2, p.254

PICU before. Dr 17 described herself as being more willing to withdraw intensive care than many of her colleagues. As she spoke, Dr 17 conveyed a sense of pride through her tone of voice, in being recognised as being more willing to withdraw or withhold treatment from disabled children.

“It is interesting that most of the time the group I work in there are two of us who have, you don’t want to be an outlier and I’m probably an outlier. Myself and one of my colleagues are known to be the doctors who will withdraw intensive therapy the most frequently, the most actively.”

However, Dr 17 suggested that her approach was out of step with that of the majority of her colleagues and expressed a sense of her own vulnerability in this regard, talking as shall be seen in chapter nine⁷²⁵ of her fear of legal or disciplinary action being taken against her because of her stance. She did however, from her tone, appear to be very confident that her approach was the right one.

Dr 18 the other PICU consultant interviewed, in contrast, used language and expressed views that had much more in common with the non-PICU doctors who worked long term with disabled children and were critical of PICU consultants. For example, she described children being admitted to PICU based on an assessment of their needs as an individual, rather than on the basis of a pre-determined heuristic, or ‘type’ of child. She spoke about the benefits of treatment as well as the burdens and emphasised the need for each disabled child to be assessed as an individual. She also talked of the importance of continually assessing children once they were receiving care. She compared her approach to her PICU colleagues, who she complained were reluctant to change a plan to withdraw treatment even when there were clear signs that a disabled child was improving. As the non-PICU consultants had done, she complained that many of her PICU consultants were unwilling to give disabled children the time they needed in PICU or parents the time she felt they needed to make difficult decisions.

⁷²⁵ Chapter nine, para 3.1, pp.365-369

Like Dr 17, Dr 18 also expressed a sense of vulnerability and isolation from her colleagues for taking a different approach to treating disabled children, despite the two doctors holding opposing viewpoints. One explanation for this is that the two consultants worked in different hospitals, perhaps in units where attitudes towards disabled children are at opposing ends of the spectrum.

Both Dr 17 and Dr 18 when asked, offered explanations as why, in their views, PICU consultants have such diverse values and opinions as to the appropriate treatment for a disabled child.

Dr 17 said:

“Part of it is cultural, part of it is religious, part of it is ethical, I’m not a religious person, but part of it is probably is religion, em, part of it is your interface and interaction with family, so what they have said to you, as opposed to what they have said to other people, part of it is your experience”

Dr 18 suggested, “*some intensivists can be quite narrow in their way of thinking.*” She also suggested doctors’ personal views and experiences could have an impact. She added that some PICU consultants often referred to disabled children as “*no hoppers*” they tend to remember just the difficult cases, and in her view, they tend to remember the unusual cases of children who stayed in PICU long-term or had bad outcomes and forget the disabled children where PICU treatment had been quick and successful.

Once again, as was seen in chapter five⁷²⁶ data from the doctors suggests that it is the doctors’ characteristics and values that influence their decisions rather than the child’s clinical presentation. Doctors using their values in this way would seem to echo the concerns highlighted in the Kennedy Debate and be in conflict with both the jurisprudence of the English High Court and the doctors’ professional guidance.

⁷²⁶ Chapter five, pp.181-236

7.1.3 Disagreement between doctors from different generations

All the doctors interviewed were senior consultants, however, they ranged in age from doctors under 45 years to over 65 years. Three older doctors spoke of younger consultants having a different attitude from their own when treating disabled child patients. Dr 24 (neurologist) who qualified in the 1970s was one. She spoke of a new generation of PICU consultants who in her view were too willing to treat disabled children without due regard to the children's best interests. She saw this being due to their disability awareness training:

“[W]e have a newer generation of younger consultants, who have had a lot of disability awareness training, so they no longer discriminate negatively and deny resources to people, but they haven't kind of acquired the wisdom.

I think [they] are now very very keen to treat absolutely everybody and technically they can do lots of things and they often don't have a real comprehension of how the child is and how they fit into the wider society and the family and so on, they don't really see beyond the walls of the intensive care unit and we may have been working with the child for the last several years and have known that it has been getting more and more difficult and the family are on their knees and actually the long term is really not good and sometimes and sometimes the first thing we have to do is we to persuade our colleagues that, alright, they are in the hospital because the ambulance turned up, but we don't infact have to put them on to a ventilator.”

Dr 14 (Other), who qualified in the very early 1980s, also expressed concerns that younger consultants reflected too little on their difficult decisions for disabled children:

“Over the last few years, maybe I am just getting old, there is a new fleet of doctors who are much less questioning, who are much more likely just to point and shoot and not to think about these bigger issues and I think there has been, as I said before, there has been a sea change in that people are much more likely just to follow parental wishes and part of that is not really weighing the burdens against benefits, just hearing the benefits, if the benefits are there are worth pursuing at any costs.”

Both the doctors suggested that the older doctors had a wisdom gained through experience, which they suggested the younger doctors lacked. However, these doctors' comments also suggest that changes in education, cultural and social attitudes and possibly even the law may have influenced the younger doctors.

What the doctors said about disagreements between doctors will now be analysed, this will be followed by discussion of what the doctors said about disagreements with parents.

7.2 Discussion

7.2.1 Softliners and Hardliners

As found in chapter five,⁷²⁷ the doctors' survey responses suggest that doctors can take very individualistic approaches to their difficult decisions for disabled children. It was seen in chapter two⁷²⁸ that both commentators and investigations identified that decisions by doctors for disabled patients can be particularly values laden. The subsequent interview discussions with doctors seem to reinforce this. However, the doctors seem to fall into two camps when making difficult decisions for disabled children. In one camp were doctors, most often but not always, who had long-term relationships with the child and family, who seemed to tailor their decisions to the individual child; the '**softliners**'. In the other camp were doctors who tended to be, but again were not always, acute specialists, called in during a crisis, who did not have long-term relationships with children or families; the '**hardliners**'. Indeed, Dr 17 who seems to fit well within this second category used this label to describe herself and fellow PICU consultants who shared her values. These labels have been adopted in the discussion in this chapter and the rest of this thesis, to describe the varying approaches of these two groups of doctors. These labels are particularly relevant to disagreements as the doctors suggest that most disagreements between doctors arise between the two camps. Moreover, the doctors also suggest that it is the hardliners doctors who have disagreements with parents but not the softliner doctors. What is meant by each term is first explained.

⁷²⁷ Chapter five, pp.181-236

⁷²⁸ Chapter two, para 8, p.72, pp.75-79 and para 10, p. 82-91

7.2.2 Softliner and hardliner characteristics

In this study, softliner doctors tend to make full and wide-ranging best interest decision for the individual child, while a hardliner tends to use heuristics and treating according to 'type' of child. The soft and hardliner distinction made here is about how the decisions are made, rather than the outcomes of those decisions. A decision led by a softliner may lead to treatment being withheld or withdrawn, but will be based on a detailed analysis of the child's best interests. It does however, seem from the doctors' comments that, in general terms, the softliners' approach tends more often to result in a child receiving treatment, whereas the hardliner doctors, will more actively withhold or withdraw treatment.

It should be noted that the hardliner and softliner classification is devised by the researcher based on analysis of all the doctors' surveys and interviews. Moreover, it is based both on the behaviours and values exhibited by the study participants themselves and also on the behaviours and values the study participants attribute to their colleagues. For example, PICU consultants are particularly identified as being hardliners, as the doctors in this study repeatedly identified PICU consultants as exhibiting what have been classified in this study as hardliner attributes.

Neurologists in contrast, seem more likely to be softliners. To say that it is the doctors' sub-specialisms which lead them to a particular 'camp' would, however, be too simplistic. As was seen earlier, Dr 18, a PICU consultant, expressed opinions that put her in the softliner camp. There were also neurologists, for example, Dr 7 who expressed some views that were more in tune with that of a hardliner. Dr 14 suggested, that it may be more a case of doctors with particular values being drawn to certain specialisms, rather than a sub-specialism moulding a doctor's values. An example of this can perhaps be seen in the spread of doctors across the sub-specialisms who said they practice a religion, if we assume that, in very broad terms, following or not following a religion can be said to give some indication of a doctors' values. As was seen in chapter

four⁷²⁹ 89% of neurologists, 50% of PICU consultants and 40% of Other Doctors said they practiced a religion. While acknowledging that the sample size of this study is small, this might suggest that doctors with certain religious values are more or less likely to become neurologists. In keeping with other studies,⁷³⁰ doctors interviewed suggested that they saw their own and colleagues' religious or non-religious values as impacting on difficult decisions for disabled children.

The divide between hardliners and softliners is not binary, but perhaps more of a spectrum of positions. For example, some of the older doctors in particular seem to straddle the two camps, most notably Drs 24 and 14.

The doctors from the two 'camps' tended to speak differently about disabled children. The softliners tended to talk about the positive aspects of a child's life, such as close loving relationships with parents and siblings. The hardliners, in contrast, tended to talk about the burdens of treatment to a child, for example the discomfort of being suctioned⁷³¹ or the pain of blood tests. Hardliners also stressed the risks of treatment, such as the possibility of a child becoming ventilator dependent and indeed, the burdens to the child of physical or cognitive impairments.

In essence the two camps seemed to approach difficult decisions for disabled children from two sides of a best interests balance sheet,⁷³² with the softliners

⁷²⁹ Chapter four, para 4.10, p.270

⁷³⁰ For example, Cuttini, M, Nadai, M, Kaminski, M, Hansen, G, de Leeuw, Lenoir, S, Persson, J, et al (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries, *The Lancet* 355.9221: 2112-2118

⁷³¹ 'Suction is used to clear retained or excessive lower respiratory tract secretions in patients who are unable to do so effectively for themselves. This could be due to the presence of an artificial airway, such as an endotracheal or tracheostomy tube, or in patients who have a poor cough due to a variety of reasons such as excessive sedation or neurological involvement.' Source <http://www.gosh.nhs.uk/health-professionals/clinical-guidelines/suction>, last accessed 20 August 2017

⁷³² The English High Court has suggested that doctors draw up a best interest balance sheet in which they list the pros and cons of treatment. In *A NHS trust v MB* [2006], EWHC 507 (Fam) Holman J made the balance sheet available in his judgment.

looking largely to the benefits of treatments and the hardliners largely to the burdens. If doctors from the two camps brought these two perspectives to difficult decisions for disabled children, in addition to seeking the views of others who know the child well, and where possible the child, it seems that optimum best interest decisions in line with professional and legal guidance would be made. However, the doctors in this study suggest this often does not happen, with instead, decisions being made by a limited number of, sometimes single doctor, using limited amounts of information known about the child and, sometimes, heuristics.

7.2.3 Ethical Implications

The importance of this to the Kennedy debate is clear. The legitimacy of doctors making life or death decisions for disabled children based solely on their personal values is clearly ethically and indeed legally questionable. Indeed, doctors rightly apply to the High Court if they believe a parent is allowing their religious values to determine the parent's assessment of their child's best interests.⁷³³ In contrast, doctors suggest a reluctance to challenge colleagues' values, or indeed treatment decisions generally when they disagree with them, either formally or informally.

Current ethical guidance on end-of-life best interest decisions provided to doctors by both the GMC and RCPCH recognises the subjective nature of qualitative best interest decisions. The RCPCH 2015 guides doctors that:

‘Courts have recognised that quality of life determinations should be based on the individual circumstances of the person taking account of his or her perceptions without discrimination; quality of life that could be considered intolerable to one who is able-bodied may not be intolerable

⁷³³ see for example *Central Manchester University Hospitals NHS Foundation Trust v A & Others* [2015] EWHC 2828 (Fam); where the hospital applied to court for an order that it was in the best interests of fourteen-month old twins with a progressive neuro-degenerative disorder to have life support removed. The parents had refused to consent to life support being withdrawn due to their Muslim faith.

to one who is born with disability or has developed long- term disability.⁷³⁴

It acknowledges that ‘all decisions about best interests of a child involve value judgements’⁷³⁵ and recognises that parties involved in a decision may disagree ‘because they have different values’⁷³⁶ Guidance from the GMC also cautions doctors: ‘You must be careful not to make judgments based on poorly informed or unfounded assumptions about the impact of a disability on a child or young person’s quality of life’.⁷³⁷ The guidance is less clear as to how doctors’ should address value judgments when they encounter them in their colleagues.

Indeed, as has already been seen, the doctors do not seem to openly challenge colleagues. They were, at least in their discussions with the researcher, highly critical of colleagues who they perceived as allowing their values to influence decisions. However, while they also acknowledged that their own values influenced their own decisions, they seemed to see no problem with that. A distinction can, however, perhaps be seen here. On the one hand, the softliners when making decisions, consult widely, looking at the child’s life more broadly, and then allowing their personal values, perhaps inevitably, to influence the decision they make, drawing on all that information. On the other hand, the hardliners talk about using heuristics as the starting point for their decisions. These heuristics, as described by the hardliners, seems to be based on assumptions, rather than informed knowledge about an individual child. It seems then that for hardliners, their values are the deciding factor rather than an inevitable gloss on a wide-ranging assessment.

⁷³⁴ Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J, (2015) ‘Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice’, *Archives of Disease in Childhood*, 100, s1-s23, Para.2.3.6

⁷³⁵ Ibid, para 2.4.2

⁷³⁶ Ibid

⁷³⁷ GMC, (2013), Good Medical Practice, GMC, London, para 96

One thing that is unclear, is the extent to which hardliner doctors when making decisions, are even aware of their colleagues' concerns. Most softliners interviewed suggest they kept their concerns to themselves.

A possible solution is recommended. Just as doctors now have a duty of candour⁷³⁸ to patients and families, perhaps what is needed is an ethical duty included in GMC guidance (or possibly even a legal duty) requiring doctors to share with colleagues information they believe is important to best interest decisions. Such a duty would perhaps empower reluctant doctors to put forward relevant information and voice concerns. It would arguably help ensure best interest decisions are ethical and indeed legally sound and considered the child's interest in the widest possible way. This is considered as a recommendation for research study in chapter ten.⁷³⁹

RCPCH 2015, published just after doctors completed their interviews, makes clear that doctors have an individual and collective responsibility to act in a child's best interests.⁹¹¹ It states:

'All members of the treating team need to be part of the decision-making process: their individual views should be sought and accorded due weight.'⁷⁴⁰

It is not known what impact, if any, this new guidance has had on doctors' decision-making.

⁷³⁸ Regulation 20, Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

⁷³⁹ Chapter ten, para 5.2, pp.400-401

⁷⁴⁰ Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J, (2015) 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice', *Archives of Disease in Childhood*, 100, s1-s23, para 3.3.1

7.2.4 Different Values between different generations of doctors

The second distinction discerned by doctors was between older, more experienced doctors and younger, newly qualified consultants, particularly between 1970s qualifiers and 1990s qualifiers, as to how they made difficult decisions for disabled children. These differences were also seen in the doctors' survey responses, as was discussed in chapter five.⁷⁴¹

These differences raise the question as to what *does* influence doctors' values? Some of the doctors made some suggestions about this in their interviews. It will be recalled that Dr 14 expressed the view that younger consultants were too willing to follow parents' wishes and there does seem to be some indication that the older generation of doctors do take a more paternalistic approach, seeing themselves more often as the decision-makers, rather seeing best interest decisions as collective decisions.

The 'hidden curriculum' was also considered earlier.⁷⁴² It is of particular interest when considering differences in practice between different generations of doctors. As was seen in chapter four⁷⁴³ the doctors in this study, were, but for one senior registrar, all senior consultants who were all influential in their hospitals, some also strategically regionally and nationally. They were arguably not just elites⁷⁴⁴, but within the medical profession, ultra-elites. If the hidden curriculum were at play, it might be expected, that junior colleagues would be highly influenced by them, in effect 'copying' how they make best interest decisions for disabled children. However, both the older consultants in their interviews, and the younger consultants in their survey responses, seem to suggest that this is not the case. Both seem to suggest that junior consultants

⁷⁴¹ Chapter five, pp.181-236

⁷⁴² Chapter three, para 2.2, pp. 100-101

⁷⁴³ Chapter four, figure 12, p.149

⁷⁴⁴ Chapter three, para 2.2, pp.98-100

are approaching difficult decisions for disabled children differently from older consultants. Both also seem to suggest that a greater recent awareness of disability and child rights, may be the catalyst for this perceived change in culture among paediatricians.

As was seen in chapter two⁷⁴⁵ the legal landscape for disabled children has changed considerably since the 1970s and this has been reflected in the professional guidance produced for doctors by bodies such as the GMC. The needs of disabled patients increasingly feature on medical undergraduate curriculum, although significant challenges remain.⁷⁴⁶ The doctors' responses suggest that this may have also had an impact on how doctors approach difficult decisions for disabled children, but it seems this might be so only for doctors who qualified since those changes came about. The older doctors in this study would have been well established in their careers before these changes happened. It seems from the doctors' comments that, at least with regard to difficult decisions for disabled children, once doctors are established in their careers, they gain confidence in their own approach and may not change the way they approach decisions when new guidance or even new legislation is published. As will be seen in part three of this thesis, if changes in the law or guidance occurred, with which they did not agree, doctors commented, as was seen with Dr 24's comments about equality training, suggest doctors can resist these changes rather than assimilate them into their practice.⁷⁴⁷

Doctors' disagreements with parents were the final area of conflict raised by the doctors. What the doctors said in this regard is now presented and discussed.

⁷⁴⁵ Chapter two, pp. 23-94

⁷⁴⁶ Tracy, J, McDonald, R (2015) Health and Disability: Partnership in Health care, *Journal of Applied Research in Intellectual Disabilities*, 28(1), pp.22-32

⁷⁴⁷ Chapter nine, para 3.4, pp.374-378

7.3 Disagreements between doctors and parents

7.3.1 What the doctors said

Several of the doctors interviewed discussed disagreements between doctors and parents as to whether a child should continue to receive treatment, although they said much less about these disagreements than they did about disagreements with colleagues. As was seen in chapter four⁷⁴⁸ nineteen doctors (57%) cited communications with parents as the most difficult aspect of their decision-making. Data from the surveyed doctors showed a difference between sub-specialities, with eight PICU consultants (80%) surveyed citing communication with parents as particularly difficult, whereas just three neurologists (33%) doing so.

Dr 17 (PICU), suggested a doctor can feel pressured to act in accordance with parental wishes, rather than a child's best wishes, to avoid complaints. Dr 14 (Other) who expressed views that could be classed as both softliner and hardliner, but taking his interview as a whole is more of a hardliner, also referred to the pressure doctors feel to follow parents' wishes:

"I think there has been a sea change in my career towards doing what the parents ask really and being rather reticent? to do what one feels is in the best interests of the child, if that is not what the parents want."

Dr 7, neurologist but a hardliner, spoke in very strong terms about parents who disagreed with doctors:

*"Their behaviour pattern is pathological, often bizarre.
I've known colleagues who have been involved in extraordinary sets of circumstances where the parental pattern of behaviour is way outside the 97th percentile"*

The hardliner doctors used language suggesting moral judgments when they talked about parents, for example describing them as "*cruel*" or "*selfish*" if parents' views as to their child's best interests differed from that of the doctors. On the hand, as reported earlier, Dr 18 (softliner) also complained that

⁷⁴⁸ Chapter four, para 5.4, p.172

some hardliner PICU consultants are too negative when talking about a disabled child to parents, ruling out, often in her view inappropriately, any possibility of a child recovering from an acute illness. Many of the comments from doctors interviewed, predominantly from the softliners, but also from some of the hardliners (for example Drs 7,14 and Dr 24⁷⁴⁹), suggest that they believe some hardliner doctors are inappropriately withdrawing or withholding treatment from disabled children.

The softliners tended to talk about parents compassionately, talking of the pain parents suffer seeing their child seriously ill and possibly dying. They tended to speak of the role parents play in supporting and caring for their children and parents' expertise in their child's health. Dr 18 (PICU), as was seen earlier, talked of the importance of giving parents time to come to terms with the fact their child was dying. Dr 32 (Other) suggested that disagreements arose not so much from differences as to a child's best interests, but, in his view, from the way in which hardliner doctors communicated with parents. He described colleagues as being too dismissive of parents' opinions and the value the parents placed on their child's life.

7.3.2 Discussion

Doctors in this study covered a full spectrum of viewpoints as to the role parents should play in end-of-life decisions, from those who saw the decision as one solely a decision for doctors, to those who saw it as the parents' decision supported by doctors. RCPCH 2015 tells doctors of a presumption that parents should always be involved in decisions to limit treatment and always be invited to take part in best interest decision-making.⁷⁵⁰ However, even when parents

⁷⁴⁹ These three doctors have all been classified as hardliners but were all situated on the spectrum of positions towards to softliner end of the hardliner doctors.

⁷⁵⁰ Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J, (2015) 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice', *Archives of Disease in Childhood*, 100, s1-s23, para. 2.4.3

are included in the decision-making process, the doctors' accounts suggested that often doctors see the purpose of discussions to convince parents to accept the doctors' view of the child's best interests, rather than an exchange of viewpoints.

This study did not seek the views of parents, but others have studied parent involvement in best interest decisions for their children. This wider research suggests parents commonly feel pressured by doctors to agree with the doctor's viewpoint as to their child's best interests.⁷⁵¹ Smith et al's⁷⁵² review of thirty-four studies of the experiences parents of children with long-term conditions, including ten studies from the UK, found parents reported 'information given quickly with little opportunity for discussion'⁷⁵³ Smith et al, along with other studies⁷⁵⁴ also report 'parents describe difficulties in obtaining information'⁷⁵⁵ to enable them to make an informed decision. This does seem to suggest that doctors' perceptions of decision-making discussions with parents and the extent, to which parents feel empowered to express their views in such discussions, may be somewhat different from parents' perceptions and experiences.

⁷⁵¹ Zaal-Schuller, IH, Willems DC, Ewals, FVPM, van Goudoever, J.B, de Vos MA, (2016) How parents and physicians experienced end-of-life decision-making for children with profound intellectual & multiple disabilities, *Research in Developmental Disabilities*, vol. 59, pp 293-293, p. 290; Brotherton, A, Abbott, J, (2012) Mothers' process of decision making for gastrostomy placement. *Qualitative Health Research*, 22(5), 587–59, p.590; de Vos, MA, Seeber AA, Gevers SK, Bos AP, Gevers, F, Willems, DL, (2015) Parents who wish no further treatment for their child, *Journal of Medical Ethics*, 41(2), 195-200, p.197; Guon, J, Wilfond, BS, Farlow, B, Bragg, T, Janvier, A (2014) Our children are not a diagnosis. The experience of parents who continue their pregnancy after a prenatal diagnosis of trisomy 13 or 18, *American Journal of Medical Genetics*, Part A, 164 A (2), 308-318, p.312

⁷⁵² Smith, J, Cheater, F, Bekker, H (2013) Parents experiences of living with a child with a long-term condition: a rapid structured review of the literature, *Health Expectations*, vol. 18, issue 4, 452-474

⁷⁵³ Ibid, p.456

⁷⁵⁴ see for example, Allen, KA (2014) Parental decision-making for medical complex infants and children. An integrated literature review, *International Journal of Nursing Studies*, 51(9), 1289-1304

⁷⁵⁵ Smith, J, Cheater, F, Bekker, H (2013) Parents experiences of living with a child with a long-term condition: a rapid structured review of the literature, *Health Expectations*, vol. 18, issue 4, 452-474

As was seen, the hardliner and softliner doctors also tended to talk very differently about parents. Indeed, hardliner doctors were more likely to report disagreements with parents than softliner doctors.⁷⁵⁶

This also echoes the findings of wider studies, which have also found that doctors with long-term relationships with a child and family are less likely to have disagreements with parents at the end of a child's life.⁷⁵⁷ Part of the reason for this may well be that the doctors who work with the families long-term, this study suggests,⁷⁵⁸ seem to have more of a shared perception of a child with the child's parents, than with some of their acute colleagues and shared perceptions as to the factors to be considered and their weight. Indeed, there are certainly echoes between the concerns the softliner doctors voiced about the values and opinions of some of their colleagues as to the quality of life of severely disabled children, with the concerns voiced by parents about the perceived negative attitudes of some doctors in other studies. Parental concerns that the lives of disabled children, particularly those with cognitive impairment are not understood or valued by doctors making end-of-life decisions about their child are widely reported in research studies.⁷⁵⁹

Comments from several of the doctors suggested that rather than using 'best interests' to open up discussions and consider the child's welfare widely, as the law and professional ethical guidance say they should, doctors seem to use the term to close down discussions; asserting their clinical expertise and dismissing

⁷⁵⁶ Chapter six, para 7.3, pp. 276-282

⁷⁵⁷ Zaal-Schuller, IH, Willems, DC, Ewals, FVPM, van Goudoever, JB, de Vos MA, (2016) How parents and physicians experienced end-of-life decision-making for children with profound intellectual & multiple disabilities, *Research in Developmental Disabilities*, vol. 59, pp 293-293, p.287

⁷⁵⁸ Chapter five, para 7, pp.235-236

⁷⁵⁹ Zaal-Schuller, IH, Willems, DC, Ewals, FVPM, van Goudoever, JB, de Vos MA, (2016) How parents and physicians experienced end-of-life decision-making for children with profound intellectual & multiple disabilities, *Research in Developmental Disabilities*, vol. 59, pp 293-293, p.291

parents' views as not in the child's best interests, without full discussion. For example, Dr 7 and Dr 24 both spoke of Muslim families who had children where there were disagreements between the doctors and the families as to whether treatment should continue. Both spoke of the families talking of their child having a quality of life worth preserving, but both doctors attributed these beliefs to the families' religious beliefs although Dr 7 added, unprompted he was unsure why he did this. Dr.18 (softliner), (echoing what Dr 32 said about doctors being dismissive of parents' views) also spoke of hardliner colleagues closing down options and discussions in the negative language they used about the children and of how compared with her hardliner colleagues, she was prepared to give families more time to come to a decision saying:

"I'm prepared to give parents, families and the child a little bit more time to come around to decisions about withdrawing or withholding, whereas they more keen to set limits and withhold and withdraw and go down the legal route and all that, rather than trying to get the parents round by talking to them and giving them a bit more time"

These findings are also echoed in studies of parents and more widely patients reported experiences of shared decisions making, for example, Joseph-Williams et al⁷⁶⁰ in their systematic review of barriers to shared decision making found

'Authoritarian or dismissive clinicians who dominate decision-making encounters, do not listen to or respect patient's concerns, or use negative verbal or non-verbal behaviours as a barrier to shared decision-making for many patients'.⁷⁶¹

The disagreements with parents raise ethical questions in respect of the child, the parents and the doctors. For the child, the same point can be made as was made earlier, to question how ethically and legally sound a decision can be deemed to be if information, in this case known to a parent and pertinent to the decision, is not considered by the decision-maker.

⁷⁶⁰ Joseph-Williams, N, Elwyn, G, Edwards, A (2014) Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared-decision making, *Patient Education & Counseling*, 94. 291-309

⁷⁶¹ Ibid, p.305

Turning to the position of the parent; the doctors in this study seemed unclear as to the extent of any ethical duty they had towards a child's parents. RCPCH 2015 describes under 'fundamental considerations' doctors' duty to a child's parents, but is less clear as to the nature and extent of that duty:

'Children's healthcare professionals have an additional duty to the child's family. Part of good paediatric care involves an assessment of the harms and benefits for parents for families as a whole. Challenge may arise when the duty to benefit the child conflicts with a duty to the parents'.⁷⁶²

Some softliner doctors suggested that the decision-making process, as much as the whether a child lives or dies, can also impact on parents' wellbeing. The doctors suggested parents want to be fully involved in the decision to ensure all relevant aspects of the child's life are fully examined and all options are fully explored. Indeed, as shall be seen in chapter nine, the few doctors who had been involved in court cases, reported that while both families and doctors felt initial concerns at lawyers being involved, they ultimately found it helpful and experienced relief that the child's best interests had been fully explored and scrutinised. Just as there seems to be a moral imperative to ensure all known information about a child is considered in best interest decisions so too, this study, alongside other research in the field, seems to suggest, that it is important for doctors to ensure that parents are fully involved in the decisions. This is critical not just to ensure an ethically sound and informed decision is made about the child, but also help safeguard the parents' mental and physical well-being, arguably also an ethically important consideration for doctors involved. Although this thesis did not examine the issue, it seems likely that a decision-making process fraught with conflict or where some doctors feel excluded from the decision for whatever reason, is also likely to have detrimental impact on the doctors involved. Indeed, the comment by Dr 14, (a doctor as was seen earlier, although close on the hardliner/softliner spectrum to

⁷⁶² Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J, (2015) 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice', *Archives of Disease in Childhood*, 100, s1-s23, para 2.4.1

softliners classified overall as a hardliner) about sleepless nights and the moral anxiety caused to the doctor mentioned earlier, suggests this is the case.

8. Conclusions

The doctors identified uncertainty and disagreements as the two biggest barriers they faced when making difficult decisions for disabled children. Although the doctors talked about these two factors as separate issues, it does seem that they are in fact closely interlinked. It seems from discussions with doctors that much of the disagreement arises because doctors approach the uncertainty they face in different ways. The softliners seem to want to address uncertainty by drawing on as many people and as much information as possible, when they lead on decisions. The softliners' approach seems to be in-line with the doctors' professional guidance and the jurisprudence of the English High Court. In contrast the hardliners seem much more inclined to fall back on heuristics, which often seem to be based on self-created rules, or at least assumptions about disabled children and their lives. This approach seems to be at odds with the wide-ranging approach advocated by the doctors' professional guidance and the courts. It also seems to be an approach which would cause Kennedy concern.

There however, seems to be a link between the softliners reluctance to challenge, in particular PICU consultants, when they think decisions are not being made in a child's best interests and to volunteer information they have about the child, and the hardliners using heuristics, it seems in part, to fill the gaps in the doctors' knowledge about an individual child. Certainly, as has been seen, wider research with doctors and parents suggests that parents' perceptions of best interest discussions can be very different from how doctors believe them to have been and perhaps intend them to be. It also seems possible that the hardliners, the softliners in this study criticise, are unaware of their softliner colleagues' concerns, or indeed, parents'.

Francis J, suggested at the end of the first judgment in recent and much publicised litigation concerning infant Charlie Gard,⁷⁶³ that in cases where there is clear disagreement between parents and doctors, third party assistance, perhaps mediation is needed to ensure a child's best interests are fully explored. In that case, there was no disagreement between the treating doctors. The doctors in this study suggest, however, that disagreement between doctors can be a common problem, with as was seen earlier⁹³⁸ twenty-six doctors in this study (78%) reporting it as something they experience when best interest decisions are being made for disabled children. As has been argued, there do seem to be some solutions, most notably for best interest decisions to be made in the full and detailed way required by the doctors' professional ethical guidance and the law. As has also been argued, when dealing with children beyond infancy, and increasingly so the older the child becomes, much of the uncertainty inherent in best interest decisions for infants can be overcome by drawing on available information about the child. Indeed, it is likely that the children who are the focus of this study have all aspects of their lives much more closely documented than their non-disabled peers.

The factors identified in this chapter it seems, are preventing the ethically sound examination of some disabled children's best interests, possibly to their detriment as well as that of their parents and the doctors involved. Perhaps, if Francis J's suggestion of mediation is seen as a step too far for day to day best interest decisions, instead, best interest discussions could be led by someone not directly involved in the care of the child, who is trained in the task, and skilled at ensuring all voices are heard, and also educated in the relevant professional guidance and law. This could be a positive way forward to help ensure best interest decisions are made for disabled children, as they should be. It could also help address the concerns the Kennedy Debate raises, particularly if it encouraged wider participation in best interest decisions by relevant expert, such as, the child's parents and education staff.

⁷⁶³ *Great Ormond Street Hospital v Yates & Gard* [2017] EWHC 972 (Fam); para 130

It can be argued that there may be occasions when treatment is needed so quickly that the time is not available to make best interest decisions in a manner that is ideal, both ethically and legally. The doctors in this study suggest that for children who are the focus of this study, such occasions will be rare as acute events can be anticipated, planned for and the agreed decision as to the child's best interests documented. Moreover, if such an event did arise, doctors are now guided by RCPCH 2015 to give treatment and then have the discussions afterwards.⁷⁶⁴ It does seem that better application by doctors of current professional ethical guidance would help address much of the uncertainty and avoid many of the disagreements which the doctors in this study identify as barriers to good best interest decisions for severely disabled children.

This thesis now moves to part three, where the focus moves from the detail of doctors' decisions for disabled children to consideration of the part played if any, by law in those decisions.

⁷⁶⁴ Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J, (2015) 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice', *Archives of Disease in Childhood*, 100, s1-s23, para 3.1.2, s.13

PART THREE

Chapter Seven

Legal Consciousness

1. Introduction

This thesis now adopts a legal consciousness theoretical framework to analyse the doctors' difficult decisions for severely disabled children. This is needed as the existing lenses used so far, do not adequately explain how doctors use and understand the law when deciding for disabled children.

'Legal consciousness' is 'a term of art within the sociology of law'.⁷⁶⁵ It is concerned with how non-lawyers⁷⁶⁶ use and understand law.⁷⁶⁷ Legal consciousness is not what individuals think about the law, nor a set of opinions about the law, but rather a process used to create meaning in everyday life in relation to the law.⁷⁶⁸ Using legal consciousness theory will help in an understanding of how the doctors make sense of their everyday difficult decisions for disabled children. It is concerned with how they 'interpret, use, and resist law, and how they embed and re-enact those meanings in their practical everyday settings'.⁷⁶⁹

⁷⁶⁵ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74

⁷⁶⁶ Although as will be seen some scholars have more recently used it to study lawyers.

⁷⁶⁷ Ewick, P, Silbey, SS, (1992) Conformity, Contestation and Resistance: An Account of Legal Consciousness, *New Eng. L. Rev*, Vol. 26, at p.731

⁷⁶⁸ Ewick, P, Silbey, SS, (1998) *The Common Place of Law, Stories from everyday life*, The University of Chicago Press, Chicago, p.247

⁷⁶⁹ Davies, M (2017) '*Law Unlimited*,' Routledge, Abington, Oxford

It was seen in chapter four⁷⁷⁰ that the doctors (but for two participants), identified end-of-life treatment decisions, as the most difficult ones they face when working with severely disabled children. It is when life and death decisions are being made, that the interface between law and medicine is at its sharpest. It was also seen in part two⁷⁷¹ that by their own account, doctors do not always consult widely, as they are guided to do by the law and their professional ethical guidance.⁷⁷² As was seen in chapter four,⁷⁷³ doctors' professional guidance, in essence, guides them to follow the law as it relates to best interest decisions for children. This thesis is interested in what the doctors say about ethics, but it is their legal consciousness, rather than their ethical consciousness, which is explored. For example, do the doctors embed the law as it is 'on the books' into their everyday lives?⁷⁷⁴ Alternatively, do they resist this interpretation of best interests and apply their own tests as to when treatment should be withheld or given? Law in this thesis is used broadly to include anything the doctors say about legal issues, including but not limited to, legislation, case law and soft law such as professional guidance.⁷⁷⁵

In adopting a legal consciousness approach, it is assumed that best interest decisions are first and foremost legal decisions, where a test established in law is the one to be applied. This assumption is based on the fact that the jurisprudence of the English High Court states clearly that the ultimate decider

⁷⁷⁰ Chapter four, para 5.1, p.168

⁷⁷¹ Chapter four, para 6, pp.173-179

⁷⁷² Chapter four, para 3, pp.142-145

⁷⁷³ Ibid

⁷⁷⁴ Merry, SE (1990) *Getting Justice and Getting Even: Legal Consciousness Among Working Class Americans*, Chicago Univ. Chicago Press, Chicago, p.5

⁷⁷⁵ For example, professional guidance issued by the Royal Medical Colleges or the General Medical Council

of a child's best interests is the court.⁷⁷⁶ In contrast, that same jurisprudence clearly states that the courts will not interfere with a doctor's clinical judgment.⁷⁷⁷ A conclusion is therefore drawn, that a best interest decision is a legal one, rather than a medical one, with medical evidence playing an important part in that decision. It is acknowledged that this interpretation of the best interest test is indicative of the author's own legal consciousness⁷⁷⁸ and that it is possible, if not likely, that as non-lawyers, the doctors in this study may see the best interest test differently.⁷⁷⁹ It is how the doctors see the best interest test, how 'it affects their lives and defines their relationships',⁷⁸⁰ which is the focus of the rest of this study.

This chapter will explain legal consciousness theory, how it will help further an understanding of doctors' best interest decisions, and where this thesis is located in the extant body of legal consciousness scholarship. The situation of study participants is significant in legal consciousness scholarship,⁷⁸¹ so this chapter will then say something about the structures, both legal and non-legal,⁷⁸² within which the doctors are situated. This chapter will conclude by summarising how using legal consciousness theory adds to an understanding of

⁷⁷⁶ *Re J (A Minor) (Wardship: Medical Treatment)* [1991] [1991] Fam. 33; [1991] 2 W.L.R. 140

⁷⁷⁷ *Ibid*

⁷⁷⁸ Chapter one, paras 5.2-5.3, pp.12-21

⁷⁷⁹ Merry, S. E. (1992). *Culture, power, and the discourse of law*. NYL Sch. L. Rev., 37, 209.

⁷⁸⁰ *Ibid*

⁷⁸¹ Marshall, AM, Barclay, S (2003) In their own words: how ordinary people construct the legal world, *Law & Social Inquiry*, 28(3), 617-628; Merry, SE (1990) *Getting Justice and Getting Even: Legal Consciousness Among Working Class Americans*, Chicago Univ. Chicago Press, Chicago; Garcia-Villegas, M (2003) Symbolic Power without violence? Critical comments on legal consciousness studies, *International Journal of Semiotics of Law*, 16(4), 363-393; Hoffman, EA, (2003) Legal consciousness and dispute resolution: different disputing behavior at two similar taxicab companies, *Law Soc. Inq*, 28:691–718

⁷⁸² Although it is acknowledged that perhaps this distinction may not be a valid one within legal consciousness theory.

paediatricians' best interest decisions for disabled children and in turn, how studying doctors' best interest decision-making, adds to an understanding of legal consciousness.

2. Development of Legal Consciousness Theory

Legal Consciousness emerged as a socio-legal theory in the USA in the 1970s and 1980s; just as in the UK, Kennedy⁷⁸³ was questioning which decisions were legitimate ones for doctors to make. Legal consciousness became more prominent and was adopted by scholars in the UK and Europe in the 1990s.⁷⁸⁴ Traditionally, it was used to examine the lives of marginalised, disempowered or discriminated against groups, where the interaction with the law was often very clear: for example, Bumiller's⁷⁸⁵ study of victims of discrimination; Merry's⁷⁸⁶ study of working class Americans; and Sarat's⁷⁸⁷ study of welfare recipients. This focus has continued in more recent times, for example, Abrego's⁷⁸⁸ study of undocumented Latinos; Blackstone's⁷⁸⁹ study of victims of sexual

⁷⁸³ Ian Kennedy, What is a Medical Decision? Astor Lecture, (Middlesex Hospital Medical School, London 1979). Also published in an amended form in Ian Kennedy, *Treat Me Right, Essays in Medical Law and Ethics*, (OUP 2001) 19-31

⁷⁸⁴ Engel, DM, (1998) 'How Does Law Matter in the Constitution of Legal Consciousness?' in Garth, BG, Sarat, A, (Eds) *How Does Law Matter?* Northwestern University Press, Illinois

⁷⁸⁵ Bumiller, K (1988) *The Civil Rights Society: The Social Construction of Victims*, John Hopkins University Press, Baltimore

⁷⁸⁶ Merry, SE (1990) *Getting Justice and Getting Even: Legal Consciousness Among Working Class Americans*, Chicago Univ. Chicago Press, Chicago

⁷⁸⁷ Sarat, A, (1990) 'The law is all over': power, resistance and the legal consciousness of the welfare poor, *Yale J. Law Humanit.* 2:343– 79

⁷⁸⁸ Abrego, LJ (2011) Legal consciousness of undocumented Latinos: Fear and stigma as barriers to claims-making for first-and 1.5-generation immigrants, *Law & Society Review*, 45(2), 337-370

⁷⁸⁹ Blackstone, A, Uggem, C, McLaughlin, H (2009) Legal consciousness and responses to sexual harassment, *Law & society review*, 43(3), 631-668

harassment, and Halliday et al's⁷⁹⁰ study of relatives of people with chronic disorders of consciousness. The 'ordinary' status of these participants emphasises the power dynamic, the comparative power of the different actors and the power of law itself.⁷⁹¹ Studying 'ordinary lives' - lives of people who commonly simply would not have access to law in its conventional sense of lawyers and courtrooms - also meant that law as it impacted on day-to-day lives, rather than in extraordinary circumstances, could be examined.

The doctors in this study, were, as has been seen, elites, in some cases, at least professionally, ultra-elites,⁷⁹² so significantly distinguishable from the participants traditionally studied by legal consciousness scholars. Doctors as a profession are also seen by those outside the profession as powerful,⁷⁹³ in stark contrast to the traditional study participants. However, legal consciousness is concerned with what the participants think and feel, and as Nimmon and Stenos-Hayes⁷⁹⁴ found in their study of thirty experienced doctors, they do not necessarily perceive themselves as being powerful. Moreover, power is relative to another individual or groups. A doctor's perception of his or her own power in a given situation, will, it seems, impact on his or her legal consciousness. It will play an important part in how the doctor defines relationships, with for example colleagues, patients or their families or indeed, with the law.

⁷⁹⁰ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74

⁷⁹¹ Ewick, P, Silbey, SS, (1992) Conformity, Contestation and Resistance: An Account of Legal Consciousness, *New Eng. L. Rev*, Vol. 26, at p. 731

⁷⁹² Chapter three, para 2.2, p.99

⁷⁹³ See for example: Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, Published in an amended form in Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, p.27

⁷⁹⁴ Nimmon, L, Stenfor-Hayes, T (2016) The 'Handling' of power in the physician-patient encounter: perceptions from experienced physicians. *BMC medical education*, 16(1), p.114

Legal consciousness scholarship takes law far beyond the study of case law. As Halliday and Morgan identify,⁷⁹⁵ if the study of law is restricted to the study of case law, with most disputes not being litigated and only a small percentage of those reaching trial, it will be restricted to the unusual, may be even unique cases, not the everyday. If only case law and lawyers are studied, the true impact of law on society will remain unknown. Legal consciousness studies are therefore the study of people's everyday experience of law. It 'decenters formal institutions and procedures and takes seriously the idea that ordinary people can be legal actors'.⁷⁹⁶

Doctors making best interest decisions illustrate this particularly vividly. When making these decisions, doctors are in possibly a unique situation of having to interpret and apply a legal test. It has been argued in part two,⁷⁹⁷ that doctors can be said to be acting in a quasi-judicial role, adjudicating as to a child's best interests, despite not being legally trained. Indeed, this in essence is what Kennedy argues.⁷⁹⁸ The nature of the doctors' decisions; the doctors' perception of the importance of law to those decisions and the doctor's training and education in law, rights and ethics are all explored in chapters eight and nine.⁷⁹⁹

This study follows a transition in legal consciousness studies, away from the study of the marginalised, disempowered or discriminated against, to the study

⁷⁹⁵ Halliday, S, Morgan, B (2013) I Fought the Law and the law Won? Legal Consciousness and the Critical Imagination, *Current Legal Problems*, vol. 66, pp.1-32, p.2

⁷⁹⁶ Marshall, AM, Barclay, S (2003) In their own words: how ordinary people construct the legal world, *Law & Social Inquiry*, 28(3), 617-628

⁷⁹⁷ Chapter five, para 5.8, p. 225

⁷⁹⁸ Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

⁷⁹⁹ Chapter eight, pp.323-346, chapter nine, pp.347-380

of more mundane, often workplace situations. For example, Cooper's⁸⁰⁰ study of local government officers; Hoffman's⁸⁰¹ study of taxi-cab Drivers; and Albiston's⁸⁰² study of workers' family and medical leave. Kennedy⁸⁰³ and Jaremba⁸⁰⁴ both push the boundaries of legal consciousness scholarship significantly, studying as they do, in the first case, American lawyers and in the second Polish judges, moving from marginalised non-lawyers to elite decision-makers and lawyers. However, the doctors in this study can, despite any perception they may have themselves, be seen to be more obviously an elite than Coopers and Hoffman's participants and - unlike Kennedy's and Jaremba's participants, are not lawyers. This thesis therefore expands on existing legal consciousness scholarship by examining a non-legal elite making a legal (albeit also medical) decision. **This is an important next step in legal consciousness studies, because it creates a bridge between existing studies. It also illustrates vividly the extent to which non-lawyers can create and apply law that affects not only their own lives, but perhaps even more so, that of their child patients and families.**

3. The creation of legal consciousness

The situation of the study's participants is important in legal consciousness studies and more is said about the doctors' situation later in this chapter. It

⁸⁰⁰ Cooper, D (1995) Local Government Legal Consciousness in the shadow of Juridification, *Journal of Law and Society*, 22(4), 506-26

⁸⁰¹ Hoffman, EA, (2003) Legal consciousness and dispute resolution: different disputing behavior at two similar taxicab companies, *Law Soc. Inq*, 28:691–718

⁸⁰² Albiston, CR (2006) 'Legal Consciousness and Workplace Rights', chapter 3 in Fleury-Steiner B, Nielsen LB (Eds), *The New Civil Rights Research, A Constitutive Approach*, Ashgate Publishers Ltd, Oxford, p.55-76

⁸⁰³ Kennedy, D (1980) 'Towards an Historical Understanding of Legal Consciousness: The Case of Classical Legal Thought in America, 1850-1940', in Spitzer S (Ed) *Research in Law and Sociology*, vol. 3, 3-24, JAI Press, Greenwich CT

⁸⁰⁴ Jaremba, U (2013) *National Judges as EU law judges: The Polish civil law system*, Martinus Nijhoff Publishers, Leiden

provides a context within which the participants' legal consciousness can be better explored and understood.⁸⁰⁵ More than that, context is an important part of creating participants' legal consciousness.⁸⁰⁶ Garcia-Villegas⁸⁰⁷ criticises Ewick and Silbey⁸⁰⁸ for failing to investigate the relationship between their participants' status in society and their legal consciousness. This seems particularly important in this study. How the doctors see themselves in society, in relation to colleagues, to patients and their families, to others, indeed to the law, will be reflected in their legal consciousness. For example, it is possible to imagine that if a doctor sees himself or herself as being in a senior position in a hierarchy in relation to a colleague or parent, the doctor will potentially perceive best interest decisions differently from a doctor who sees him or herself as working with colleagues and parents in an equal partnership. Indeed, the central tenet of Hoffman's⁸⁰⁹ study is the way in which each group of taxi drivers, in two very different taxicab firms,⁸¹⁰ create a different legal consciousness. In chapter eight⁸¹¹ it will be seen that two PICU consultants working in different units seem to have very different approaches to best interest decisions and different legal consciousness. However, while a participant's situation seems important in creating his or her legal consciousness, there are perhaps surprising similarities to be found between

⁸⁰⁵ Marshall, AM, Barclay, S (2003) In their own words: how ordinary people construct the legal world, *Law & Social Inquiry*, 28(3), 617-628, p. 617

⁸⁰⁶ Merry, SE (1990) *Getting Justice and Getting Even: Legal Consciousness Among Working Class Americans*, Chicago Univ. Chicago Press, Chicago

⁸⁰⁷ Garcia-Villegas, M (2003) Symbolic Power without violence? Critical comments on legal consciousness studies, *International Journal of Semiotics of Law*, 16(4), 363-393, p.386

⁸⁰⁸ Ewick, P, Silbey, SS, (1992) Conformity, Contestation and Resistance: An Account of Legal Consciousness, *New Eng. L. Rev.*, Vol. 26, & Ewick, P, Silbey. SS (1999) Common Knowledge and Ideological Critique, *Law and Society Rev.*, 33, 1027

⁸⁰⁹ Hoffman, EA, (2003) Legal consciousness and dispute resolution: different disputing behavior at two similar taxicab companies, *Law Soc. Inq.*, 28:691-718

⁸¹⁰ One was co-operative and the other a more traditional hierarchical company.

⁸¹¹ Chapter eight, pp.323-346

quite disparate groups. For example, Cooper⁸¹² reports finding unexpected similarities in the legal consciousness of the relatively socio-economically secure local government officers in her study, to the welfare poor in Sarat's.⁸¹³ Although Cooper does not make the point, this could perhaps be because, as the Nimmon and Stenos-Hayes⁸¹⁴ study mentioned earlier found, some individuals may not perceive themselves as powerful and influential, as others do. Legal consciousness is essentially about self-perceptions. Groups perceived by others as elite, may perceive themselves as vulnerable. As will be seen in chapter nine,⁸¹⁵ this seems to be important in this study.

What the literature makes very clear is that the creation of legal consciousness is a complex process. Social practices;⁸¹⁶ unconscious ideas;⁸¹⁷ habitual patterns of talk and action;⁸¹⁸ background assumptions⁸¹⁹ and past experience⁸²⁰ all play an important part. Legal consciousness is not a passive

⁸¹² Cooper, D (1995) Local Government Legal Consciousness in the shadow of Juridification, *Journal of Law and Society*, 22(4), 506-26, p.510

⁸¹³ Sarat ,A, (1990) 'The law is all over': power, resistance and the legal consciousness of the welfare poor, *Yale J. Law Humanit.* 2:343– 79

⁸¹⁴ Nimmon, L, Stenfors-Hayes, T (2016) The 'Handling' of power in the physician-patient encounter: perceptions from experienced physicians. *BMC medical education*, 16(1), p.114

⁸¹⁵ Chapter nine , para 3, pp.361-378

⁸¹⁶ Marshall, AM, Barclay, S (2003) In their own words: how ordinary people construct the legal world, *Law & Social Inquiry*, 28(3), 617-628, p.625; Silbey, SS (2005) After legal consciousness, *Annu. Rev. Law Soc. Sci.* 1, 323-368, p. 327 & Garcia-Villegas, M (2003) Symbolic Power without violence? Critical comments on legal consciousness studies, *International Journal of Semiotics of Law*, 16(4), 363-393, p.365

⁸¹⁷ Nielsen, B, (2000) Situating Legal consciousness: Experiences and Attitudes of Ordinary Citizens About Law and Street Harassment *Law and Society Review*, p.1058

⁸¹⁸ Merry, SE (1990) *Getting Justice and Getting Even: Legal Consciousness Among Working Class Americans*, Chicago Univ. Chicago Press, Chicago, p. 5

⁸¹⁹ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74, p. 57

⁸²⁰ Marshall, AM, Barclay, S (2003) In their own words: how ordinary people construct the legal world, *Law & Social Inquiry*, 28(3), 617-628, p.622

reaction to the law. It is a dynamic interaction by which individuals construct their understanding of law, creating different meanings of the law based on their individual identities.⁸²¹ This can be seen in this thesis in the way individual doctors create different understandings of best interests, through their interpretations of the test in the light of their experiences, assumptions, unconscious ideas and professional and personal backgrounds.

Central to legal consciousness theory is the belief that law does not just construct individuals' lives, but individuals also construct the law.⁸²² Individuals are seen not only to challenge existing meanings and understandings about their lives by drawing on the law, but also to draw on existing non-legal discourses to challenge changes in the law.⁸²³ Individuals constantly interpret the law and in so doing create 'new versions of legality'.⁸²⁴ Thus, for legal consciousness scholars, '[L]aw acts as an important site for the construction of meaning'.⁸²⁵ As will be seen in chapter nine,⁸²⁶ the doctors in this study can clearly be seen to create their own meanings of best interests, drawing, in particular, on medical but also wider discourses, to recreate the law and at times challenging the law (whether consciously or not). It seems that the unique position of the doctors interviewed in this thesis, as non-lawyers but undertaking

⁸²¹ Fleury-Steiner, B, Nielsen, LB, (2006) *The New Civil Rights Research, A Constitutive Approach*, Ashgate Publishers Ltd, Oxford

⁸²² Mezey, N (2001) Out of the ordinary: law, power, culture, and the commonplace, *Law & Social Inquiry*, 26(1), 145-167, p.148

⁸²³ Ibid p.6

⁸²⁴ Marshall, AM, Barclay, S (2003) In their own words: how ordinary people construct the legal world, *Law & Social Inquiry*, 28(3), 617-628, p. 618

⁸²⁵ Merry, SE (1990) *Getting Justice and Getting Even: Legal Consciousness Among Working Class Americans*, Chicago Univ. Chicago Press, Chicago, p. 2

⁸²⁶ Chapter Nine, pp. 347-380

what is clearly, at least to lawyers,⁸²⁷ an obviously legal task, emphasises very vividly, the way in which non-lawyers can and do construct law. Shining a light on the way in which non-lawyers create law is important. It allows for questions to be asked about the legitimacy of what individuals, here the doctors, are doing. They can be asked, as Kennedy⁸²⁸ did, about doctors' competence and expertise to make best interest decisions. Questions can also be asked about whether sufficient checks and balances are in place to protect those, in the case of this study, severely disabled children, whose lives are affected by the actions and decisions of these law creators.

This process of construction is seen by scholars⁸²⁹ to be a collective phenomenon, the interplay between members of a group being an important part of the creative and construction process. Engel sees this as the attraction of legal consciousness theory as it enables researchers to study the thoughts of whole groups or even whole cultures.⁸³⁰ This is an obvious attraction of this theory for this study of doctors.

Other scholars talk much more of individuals, describing, for example, legal consciousness as 'the interplay between individuals and the law'.⁸³¹ Silbey is critical of the individual focus, seeing it as weakening the power and potential of legal consciousness theory as an analytical tool, making the focus too

⁸²⁷ For example: Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, Published in an amended form in Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31.

⁸²⁸ Ibid

⁸²⁹ Silbey, SS (2005) After legal consciousness, *Annu. Rev. Law Soc. Sci.*, 1, 323-368, p.333

⁸³⁰ Engel, DM, (1998) 'How Does Law Matter in the Constitution of Legal Consciousness?' in Garth, BG, Sarat, A, (Eds) *How Does Law Matter?* Northwestern University Press, Illinois, p.111

⁸³¹ Fleury-Steiner, B, Nielsen, LB, (2006) *The New Civil Rights Research, A Constitutive Approach*, Ashgate Publishers Ltd, Oxford, p. 4

narrow.⁸³² Silbey went as far as to say an individual focus made the purpose of continuing legal consciousness as a discipline questionable.⁸³³ Marshall⁸³⁴ takes a different view, seeing the emphasis on the individual as allowing researchers to explain why wide variations in legal consciousness can occur in individuals who seem to be 'similarly situated.'⁸³⁵

Marshall's argument does seem to have merit in the context of doctors in this study. Doctors who appear to be similarly situated, for example working as PICU consultants, seem to have very different legal consciousness. However, as was said earlier, the creation of legal consciousness is a complex process. All individuals are multi-dimensional, with cotemporaneous membership of several different groups. A particular group is also likely to impact on the individuals within it differently, perhaps depending, to an extent, as to how strongly the individual identifies with that group. To give an example, a doctor may identify strongly with colleagues, adopting their values and beliefs. Another doctor in the same group may reject those values and beliefs and so the group may help shape their legal consciousness very differently. Because individuals are so multi-dimensional it is also very difficult to say with certainty which groups to which an individual belongs, contributed to the creation of an individual's legal consciousness; nor indeed, which individuals within a group and which aspects of those individuals, contributed to a group legal consciousness. Presumably the answer is that all the groups and individuals contributed, but it is unknown to what extent.

⁸³² Silbey, SS (2005) After legal consciousness, *Annu. Rev. Law Soc. Sci.*, 1, 323-368, p.324

⁸³³ Ibid

⁸³⁴ Marshall, AM, Barclay, S (2003) In their own words: how ordinary people construct the legal world, *Law & Social Inquiry*, 28(3), 617-628

⁸³⁵ Ibid, pp.263-264

There is also merit in Silbey's argument that legal consciousness loses its point if it begins examining individuals rather than groups. The question, then, becomes why study individuals if they are all so different? Can anything be learnt from studying the legal consciousness of an individual that can helpfully be more widely applied? The answer seems to be that studying individuals as individuals does not add a great deal, but individuals' legal consciousness need to be studied in the context of the group. This then gives a better understanding of the group's legal consciousness, not least how powerful it is and also perhaps which characteristics of the individuals within it, helped establish it. But perhaps, this debate is unimportant since, as Halliday et al suggests, 'although individuals have attitudes, attitudes are not individual. Orientations towards legality are social rather than individual'.⁸³⁶ Both individual and group attitudes and consciousness, as well as the relationship between the two, are therefore important subjects of study.

4. Choosing not to use the law & the impact of the unconscious on legal consciousness

In addition to examining how people think about the law, understand it and how the law affects their everyday lives, legal consciousness⁸³⁷ is also the study of when choices are made *not* to use the law.⁸³⁸ Alongside this, it is concerned with how unconscious accepted ways of thinking about law affect people's decisions.⁸³⁹ Indeed, Merry talks of legal consciousness as: '[t]he way people

⁸³⁶ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74, p. 69

⁸³⁷ Nielsen, B, (2000) Situating Legal consciousness: Experiences and Attitudes of Ordinary Citizens About Law and Street Harassment *Law and Society Review*, p. 1058

⁸³⁸ Fleury-Steiner, B, Nielsen, LB, (2006) *The New Civil Rights Research, A Constitutive Approach*, Ashgate Publishers Ltd, Oxford, p. 326

⁸³⁹ Nielsen, B, (2000) Situating Legal consciousness: Experiences and Attitudes of Ordinary Citizens About Law and Street Harassment *Law and Society Review*, p. 1058

conceive of the 'natural' and normal way of doing things.'⁸⁴⁰ This is pertinent to this thesis in several ways. First, this 'avoiding the law' aspect of legal conscience will be explored in the context of doctors resisting having a particular conception of best interests imposed upon them. Secondly, as was seen in chapter six, doctors sometimes choose to challenge others' conceptions of a child's best interests when they disagree, but not at other times. Thirdly, the doctors discussed, as was seen in chapter six, their colleagues' attitudes towards disabled children and their own perceptions of the impact these doctors' attitudes have on their best interest decisions. An accepted way of thinking amongst doctors, in this case about disabled children, seems to have a direct impact on how doctors formulate their best interest decisions.

5. Law 'on the books' and law 'in action'

Legal consciousness studies are also concerned with filling the gaps between the law as it appears in the statutes and court judgments (law on the books) and law as it impacts on ordinary people's everyday lives, making legal consciousness theory part of the tradition in law and society scholarship of exploring the gap between 'law on the books and law in action'.⁸⁴¹ The question of the extent to which doctors are, or are not, making best interests decisions, as they are guided to do by their professional ethical guidance⁸⁴² and the English High Court, is an important and repeated theme in this thesis. The subject matter of this thesis also helps exemplify why examining these gaps is important. By examining how doctors in everyday practice make best interest decisions for disabled children, already in part two, this thesis has found gaps between what doctors are guided to do and what doctors are actually doing

⁸⁴⁰ Merry, SE (1990) *Getting Justice and Getting Even: Legal Consciousness Among Working Class Americans*, Chicago Univ. Chicago Press, Chicago, p.5

⁸⁴¹ Marshall, AM, Barclay, S (2003) In their own words: how ordinary people construct the legal world, *Law & Social Inquiry*, 28(3), 617-628

⁸⁴² Chapter four, para 3, pp.142-145

when they make best interest decisions. If no gaps had been found, the question asked by Kennedy (in summary whether doctors should be making these decisions)⁸⁴³ would still have remained, but seemed less problematic. This is because, if doctors were acting as guided by their professional bodies and case law, this suggests, some external oversight. Doctors are acting according to accepted, well considered norms. However, as this thesis has found, by doctors' own reports, some doctors are not doing so, but rather formulating their own conception of the law in this regard, this raise legitimate concerns. It suggests that Kennedy's concerns are justified, not just in theory, but also in practice. It then becomes unclear how doctor's decisions are regulated on a day-to-day basis. It raises the possibility that disabled children's best interests may not be appropriately assessed. This, in turn, raises the possibility that disabled children may either receive medical treatment or have it withheld inappropriately. The emotive nature of doctors' decisions; the potential life or death of a child, brings into very sharp focus the importance of exploring the gaps between 'law on the books' and 'law in action', in a way that less emotive and more prosaic subjects perhaps do not.

Another question legal consciousness scholars are keen to address is how, if there are consistent gaps between law on the books and law in action, law sustains its institutional power.⁸⁴⁴ Garcia-Villegas suggests that one of the ways this can happen is through the selective use of interventions.⁸⁴⁵ This is relevant to what doctors said at interview about choosing whether or not to challenge colleagues, formally or informally, if they are concerned that a child's

⁸⁴³ Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, published in an amended form in Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

⁸⁴⁴ Silbey, SS (2005) After legal consciousness, *Annu. Rev. Law Soc. Sci.*, 1, 323-368, p. 323

⁸⁴⁵ Garcia-Villegas, M (2003) Symbolic Power without violence? Critical comments on legal consciousness studies, *International Journal of Semiotics of Law*, 16(4), 363-393, p.390

best interests are not being properly addressed.⁸⁴⁶ It is also relevant to how judges chose or otherwise to intervene in doctors' best interest decisions, a topic touched on briefly in this thesis⁸⁴⁷ and recommended for further study.⁸⁴⁸

A legal consciousness approach suggests that law as found in the books, has less power than the perceptions of law created by those ordinary people who would invoke or violate it.⁸⁴⁹ It suggests further that the real impact and importance of law is found not solely in what the statute books and court judgments say, but in how ordinary people, (meaning in this thesis non-lawyers), see and construct law.⁸⁵⁰ In the context of this thesis, this can be seen as the power of best interest decisions residing with the doctors. However, the extent of this power will depend on how the individual doctors conceptualise best interest decisions. For example, a doctor who takes a paternalistic approach, making the decision without consultation will have a tight grip on that power, whereas a doctor who consults widely will share that power. Relationships are important in the construction of legal consciousness and this can be seen vividly here. The relationships a doctor has with their colleagues, the child, and parents will impact on the extent the doctor shares decision-making. Also, it seems the extent to which a doctor maintains power will be affected by the legal consciousness of those around him or her. For example, a doctor will lose power if challenged by another doctor or parent, particularly if

⁸⁴⁶ Chapter six, para 7, pp.261-282

⁸⁴⁷ Chapter two, para 3, p.37

⁸⁴⁸ Chapter ten, para 5.1.4, pp.399-400

⁸⁴⁹ Marshall, AM, Barclay, S (2003) In their own words: how ordinary people construct the legal world, *Law & Social Inquiry*, 28(3), 617-628, p.622

⁸⁵⁰ Fleury-Steiner, B, Nielsen, LB, (2006) *The New Civil Rights Research, A Constitutive Approach*, Ashgate Publishers Ltd, Oxford

that challenge is a formal one, such as applying to court, where the power will be transferred to the court.

Having established what legal consciousness theory is and why it is used in this thesis, consideration is now given to the categories of legal consciousness identified by some of its leading scholars.

6. Categories of legal consciousness

Legal consciousness scholars have identified various categories or schema of legal consciousness.

Ewick⁸⁵¹ and Silbey,⁸⁵² two of the pre-eminent legal consciousness scholars, identified three categories or schema of legal consciousness. They labelled them 'before the law';⁸⁵³ 'with the law';⁸⁵⁴ and 'against the law.'⁸⁵⁵ They saw these schema, as together encompassing the fully range of conventional experiences of the law.⁸⁵⁶ The schema are not representations of what individuals think about the law,⁸⁵⁷ but are drawn on by individuals to create legal meaning.⁸⁵⁸ Each schema will now be considered.

⁸⁵¹ Ewick, P, Silbey, SS, (1992) *Conformity, Contestation and Resistance: An Account of Legal Consciousness*, *New Eng. L. Rev*, Vol. 26, at p. 731; Ewick, P, Silbey, SS, (1998) *The Common Place of Law, Stories from everyday life*, The University of Chicago Press, Chicago & Ewick, P, Silbey. SS (1999) *Common Knowledge and Ideological Critique*, *Law and Society Rev*, 33, 1027

⁸⁵² *Ibid* and Silbey, SS (2005) *After legal consciousness*, *Annu. Rev. Law Soc. Sci*, 1, 323-368

⁸⁵³ Ewick, P, Silbey, SS, (1998) *The Common Place of Law, Stories from everyday life*, The University of Chicago Press, Chicago, p.74

⁸⁵⁴ *Ibid*, p.129

⁸⁵⁵ *Ibid*, p.184

⁸⁵⁶ *Ibid*, p.248

⁸⁵⁷ *Ibid*, p.247

⁸⁵⁸ *Ibid*

6.1 'Before the Law'

Ewick and Silbey⁸⁵⁹ adopted this phrase from Franz Kafka's novel 'The Trial':⁸⁶⁰ 'Before the law stands a doorkeeper on guard...barring entry to the door'.⁸⁶¹ The Trial tells the story of Joseph K, a young banking official arrested and prosecuted by a remote, faceless authority. Neither Joseph nor the reader are ever made aware of Joseph's alleged crime. Ewick and Silbey identify a depiction of the law as remote, not just in terms of distance, but also in terms of power, being kept at a distance by a hierarchy of gatekeepers.⁸⁶²

'Before the law' sees the law as taking place within set locations, for example a court room or lawyer's office, rather, in contrast to other schema, as a system of ideas or persons.⁸⁶³ The law is distant, objective and impartial.⁸⁶⁴ The law has defined limits and boundaries; both in terms of who can take part and where the law takes place. These are set by the law's own rules and regulations.⁸⁶⁵ In this schema the law is not part of everyday life and only impacts on everyday life when things go wrong.⁸⁶⁶ Ewick and Silbey see the law dehumanising.⁸⁶⁷ The only way that the law is expressed by humans is through the actions of those employed within the law, such as judges or lawyers, or those acting in an

⁸⁵⁹ Ibid, p. 74

⁸⁶⁰ Kafka, F, (2000) *The Trial*, Penguin Classics, London (first published 1925)

⁸⁶¹ Ewick, P, Silbey, SS, (1998) *The Common Place of Law, Stories from everyday life*, The University of Chicago Press, Chicago, p. 74

⁸⁶² Ibid

⁸⁶³ Ibid, pp. 75-76

⁸⁶⁴ Ibid, p. 76

⁸⁶⁵ Ibid

⁸⁶⁶ Ibid, p.77

⁸⁶⁷ Ibid, p.78

official capacity such as jurors.⁸⁶⁸ Law here is depicted as housed in imposing and scary buildings such as courts or as enacted by oppressive bureaucratic agencies, with lawyers taking the dominant roles.⁸⁶⁹ Law is a place to which ordinary people have to be taken or visit. However, there are risks in going to law, as in doing so the individual in effect hands over their problem (and with it their power) to the lawyers⁸⁷⁰ to seek a solution⁸⁷¹ As well as being a depiction of the law in the legal consciousness of some ordinary people, Ewick and Silbey report that often legal professionals express this schema of legal consciousness,⁸⁷² which it seems is likely to reinforce this schema within the legal consciousness of ordinary people engaging with them, especially if the ordinary people look up to the lawyers as the experts in law. This once again shows the importance of relationships in the construction of a legal consciousness. This expression of legal consciousness is seen in doctors, if any, who see the law just in terms of litigation; as something that is potentially a threat to them both professionally and personally.

6.2 'With the Law'

This conception of the law differs from 'before the law' both in terms 'form and content as well as its location in social space'.⁸⁷³ In contrast to the distance between ordinary life and the law found in the 'before the law' conception, here

⁸⁶⁸ Ibid, p.78

⁸⁶⁹ Ibid, p.158

⁸⁷⁰ A parallel can be seen with Nils Christie's description of the state stealing or taking over people's conflicts to the extent that the people at the centre of the conflict are almost if not completely forgotten. See Christie, N (1977) Conflict as Property, *The British Journal of Criminology*, Vol 17, Issue 1, pp. 1-15

⁸⁷¹ Harding R (2006). "Dogs are 'registered', People shouldn't be' *Legal Consciousness and Lesbian and Gay Rights*", *Social and Legal Studies*, 15 (4),511-533

⁸⁷² Ewick, P, Silbey, SS, (1998) *The Common Place of Law, Stories from everyday life*, The University of Chicago Press, Chicago, p.106

⁸⁷³ Ibid, p.129

law is accessible, present in ordinary life.⁸⁷⁴ While 'before the law' is legality dehumanized⁸⁷⁵ 'with the law' can be empowering, helping people to achieve their aims.⁸⁷⁶ However, the law is not without constraints. Holders of a 'with the law' legal consciousness understand that they are controlled by rules and regulations.⁸⁷⁷ For example, the law is more accessible to some than to others, not least because of the costs involved. How well the law can be invoked can also depend on an individual's level of knowledge and experience.⁸⁷⁸

In this thesis, this conception of legal consciousness would perhaps be seen in doctors, if any, who have a good awareness of how best interests are conceptualised in their professional guidance, but are also aware of barriers - whether that be resources or an opposing opinion from another doctor - that could impact on the doctor's ability to ensure a decision is made in what he or she believes to be the child's best interests.

Within this conception of legality, the law is a game which people either play or refrain from playing. Ewick and Silbey describe the law as making tools, resources and specific language available.⁸⁷⁹ The best interests test could be seen as each of these. However, they stress that law is much more than this and it is wrong to see the law just as a tool or set of tools.⁸⁸⁰ For example, law within this schema is often used to communicate between actors. Ewick and Silbey argue that referring to law as a tool overlooks that legality is about

⁸⁷⁴ Ibid, p.132

⁸⁷⁵ Ibid, p.129

⁸⁷⁶ Ibid, p.131

⁸⁷⁷ Ibid

⁸⁷⁸ Ibid, p.132

⁸⁷⁹ Ibid

⁸⁸⁰ Ibid, p.133

relationships. Talking about law as a tool fails to capture the interactive and social aspect of law.⁸⁸¹ From what has already been said, it can be seen that this seems possibly to apply to best interest decisions. The importance of relationships when making best interests was seen in chapter six.⁸⁸² In chapter nine, it will be seen how these help shape a doctors' legal consciousness.⁸⁸³

Lawyers still play an import role in this conception of the law. They are 'the go between, the translators, initiators into the rules of the game'.⁸⁸⁴ Lawyers could help or hinder by creating obstacles.⁸⁸⁵ However, whereas in the 'before the law' schema the law was a place only for lawyers or those there for an official reason, 'with the law', non-lawyers are actively involved not just as legal parties but also recreating and challenging the law.⁸⁸⁶ This, in turn, can create challenges for the legal professionals, as they are no longer the only experts with access to the law.

6.3 'Against the Law'

Within this conception, legality is described as a net, which traps ordinary, marginalised people, forcing them to struggle for freedom.⁸⁸⁷ A need for resistance to the law is dominant here. Legality here is untrustworthy and to be avoided. Ewick and Silbey describes it as arbitrary, capricious and dangerous, a place of last resort.⁸⁸⁸ It lacks a moral compass and seems to embrace both

⁸⁸¹ Ibid, p.134

⁸⁸² Chapter six, pp. 237-284

⁸⁸³ Chapter nine, pp.347-380

⁸⁸⁴ Ewick, P, Silbey, SS, (1998) *The Common Place of Law, Stories from everyday life*, The University of Chicago Press, Chicago, p.153

⁸⁸⁵ Ibid, p.15

⁸⁸⁶ Ibid, p.164

⁸⁸⁷ Ibid, p.184

⁸⁸⁸ Ibid, p.194

violence and power.⁸⁸⁹ When the law cannot be avoided actors reluctantly submit themselves to it.⁸⁹⁰

Ewick and Silbey's description of 'against the law' has some similarities with their description of 'before the law', since both are bureaucratic, formal and remote. However, whereas law in 'before the law' is seen as grand and imposing, in 'against the law,' law is more menacing, unable to respond (in the actors' eyes) to the sort of ordinary troubles that impact on their everyday lives.⁸⁹¹

Echoes of this schema, as will be seen in chapter nine,⁸⁹² were found in the comments made by doctors in this study when asked directly about the law. Several doctors express a view that lawyers and the courts just don't understand medicine and the complexities of best interest decision-making. One doctor expressed similar views about legislation enacted to protect disabled people from discrimination. Some doctors expressed a sense of finding the law as a threat to them, but law was also, in their view, not nuanced enough to be reflect the complexities of their decisions or the realities of day-to-day hospital life.

7. Criticisms of Ewick and Silbey's schema

While being a dominant influence on legal consciousness scholarship, Ewick and Silbey's schema has not been without its critics, most notably Mezey.⁸⁹³ In

⁸⁸⁹ Ibid

⁸⁹⁰ Ibid, p.195

⁸⁹¹ Ibid, p.198

⁸⁹² Chapter nine, pp. 347-380

⁸⁹³ Mezey, N (2001) Out of the ordinary: law, power, culture, and the commonplace, *Law & Social Inquiry*, 26(1), 145-167

her critique of Ewick and Silbey,⁸⁹⁴ Mezey questions where law is to be found in Ewick and Silbey's conception of legal consciousness.⁸⁹⁵ Mezey criticizes Ewick and Silbey for failing to draw any clear distinction at all between law and society, to the extent that law as an entity seems to no longer exist.⁸⁹⁶ There is some merit in this criticism, particularly in Ewick and Silbey's account of the 'with the law' schema⁸⁹⁷ where law is so much a part of ordinary life that it is difficult to identify what makes something law at all. But perhaps that is the point, that law is part of every aspect of life; it is all embracing. A doctor can be seen as entering into a series of relationships with patients, families and colleagues throughout a working day. A doctor can also be seen to be making a series of decisions throughout the day; which patients to see; which tests to do; which colleagues to refer to or consult with; what information to share, to name a few. Each of those decisions and interactions has the potential to create law. For example, if as been posited, the best interest test is a legal test, a doctor can be seen to create and recreate the test in his or her choice of, for example, who the doctor includes in the decision-making process; which factors the doctors considers relevant to the test and the weight the doctor puts both on each of those factors and also on the views of the others, if anyone, involved in the decision-making process. This illustrates the important point that law is in essence about the regulation of relationships and good best interest decision-making can be seen as a series of communications and dependant upon the relationships of those communicating. Studying doctors situated as they seem to be when making best interest decisions, somewhere between non-lawyers and lawyers, helps to illustrate the connection between law as it is conceived by

⁸⁹⁴ Ewick, P, Silbey, SS, (1998) *The Common Place of Law, Stories from everyday life*, The University of Chicago Press, Chicago

⁸⁹⁵ Mezey, N (2001) Out of the ordinary: law, power, culture, and the commonplace, *Law & Social Inquiry*, 26(1), 145-167, p.153

⁸⁹⁶ Ibid

⁸⁹⁷ Ewick, P, Silbey, SS, (1998) *The Common Place of Law, Stories from everyday life*, The University of Chicago Press, Chicago, pp129-164

legal consciousness scholars, part of everyday life and relationships and law as it appears in the books⁸⁹⁸ and is taught to and practices by lawyers.

8. Developing Ewick & Silbey's schema

Harding,⁸⁹⁹ Halliday & Morgan⁹⁰⁰ and Halliday, Kitzinger and Kitzinger⁹⁰¹ are UK-based legal consciousness scholars who have taken forward Ewick and Silbey's work, adapting and developing legal consciousness theory. Both Harding and Halliday et al, draw on Ewick and Silbey's schema of 'with' and 'against' the law. In her study of the family lives of lesbians and gay men, Harding focuses on the concept of resistance within her participants' legal consciousness. She identifies three types of resistance to law; stabilising resistance,⁹⁰² moderating resistance⁹⁰³ and fracturing resistance.⁹⁰⁴ Harding's stabilising resistance involves individuals or groups challenging power, often the power of government, not through deliberate acts of challenge such as protest marches or perhaps legal challenges in the court, but by continuing to be themselves, despite this being outside the norm.⁹⁰⁵ Harding gives the example

⁸⁹⁸ Merry, SE (1990) *Getting Justice and Getting Even: Legal Consciousness Among Working Class Americans*, Chicago Univ. Chicago Press, Chicago

⁸⁹⁹ Harding, R, (2010) *Regulating Sexuality: Legal Consciousness in lesbian and gay lives*, Routledge, Abingdon

⁹⁰⁰ Halliday, S, Morgan, B (2013) I Fought the Law and the law Won? Legal Consciousness and the Critical Imagination, *Current Legal Problems*, vol. 66, pp.1-32

⁹⁰¹ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74

⁹⁰² Harding, R, (2010) *Regulating Sexuality: Legal Consciousness in lesbian and gay lives*, Routledge, Abingdon, p.12

⁹⁰³ Ibid

⁹⁰⁴ Ibid

⁹⁰⁵ Ibid, p.46

of being gay and lesbian parents⁹⁰⁶ or binge drinking,⁹⁰⁷ acts outside the norm or challenging governmental guidance but not undertaken with the purpose of challenge. Those practising stabilising resistance, do so alongside those living within the norm, for example, heterosexual parents, the challenge or resistance comes from living differently from the norm. Stabilising resistance illustrates that wherever there is an expected norm, those outside that norm are resistant.⁹⁰⁸ Harding sees stabilising resistance as the antithesis to what she describes as 'disciplinary power relations'.⁹⁰⁹ In other words, individuals or groups resisting power by continuing to act as they wish to act, rather than feeling pressured to conform to the norm society is attempting to impose upon them. Harding draws parallels between stabilising resistance, and Ewick and Silbey's 'against the law' schema.⁹¹⁰ Harding argues that this form of resistance emphasises the relational nature of power. The norm she argues only needs to be enforced through disciplinary mechanisms because everyone does not automatically comply with the norm. Harding's explanation of stabilising resistance is used to inform the analysis of what the doctors said about how they make their difficult decisions.

Harding identifies two other forms of resistance, moderating and fracturing resistance as being particularly helpful at illustrating resistance in relation to sexuality,⁹¹¹ but that does not mean these forms of resistance could not potentially be applied to and illuminate other situations. Moderating resistance, Harding explains is about openly challenging the status quo, not necessarily bringing about immediate change, although this could be the aim; but it

⁹⁰⁶ Ibid, p.45

⁹⁰⁷ Ibid pp.45-46

⁹⁰⁸ Ibid

⁹⁰⁹ Ibid

⁹¹⁰ Ibid

⁹¹¹ Ibid p. 13

highlights opposition to government or other power and in doing so shifting the debate.⁹¹² This form of resistance often involves public protest; Harding cites the 2003 marches against the invasion of Iraq in the UK or annual gay pride marches, as examples of this form of resistance.⁹¹³ Harding identifies the defining element of fracturing resistance as being an act of resistance requiring immediate or almost immediate reaction by the government or power being challenged.⁹¹⁴ Those resisting will be doing so publicly, as with moderating resistance, but the act may be violent, as in the 2005 Paris riots;⁹¹⁵ but this will not necessarily be so. Harding gives the example of 2004 mass lesbian and gay weddings in San Francisco as an example of non-violent fracturing resistance.⁹¹⁶ In both Harding's examples the state was forced to act quickly, in the former with the deployment of police and in the later with the actions of the mayor who had issues the marriage certificates being declared ultra vires by the court.⁹¹⁷ Although the act of resistance and the government's reaction to it causes a fracture in the relationship between the parties, Harding says the word fracture was chosen, as there is always the possibility of the fractured relationship to heal.⁹¹⁸ The fact that the nature of the resistance are labelled by the nature of the response by the power holder to it, once again emphasises the relational nature of legal consciousness.

Harding's schema of resistance will be used as part of the analysis of doctors' best interest decision-making. Consideration will be given as to whether the

⁹¹² Ibid, pp.46-47

⁹¹³ Ibid

⁹¹⁴ Ibid, p.48

⁹¹⁵ Ibid

⁹¹⁶ Ibid

⁹¹⁷ Ibid, p. 48-49

⁹¹⁸ Ibid, p. 47

doctors seem to express resistance and if so, can that resistances be described as stabilising, moderating or fracturing. This will help in an understanding of doctors' legal consciousness by showing how and if doctors are resisting and also explore whether Harding's three classifications can be applied to wider situations.

Like Harding, Halliday et al acknowledge the influence Ewick and Silbey's three schema had on their classifications of legal consciousness; namely 'law as a sword'; 'law as a shield' and 'law as a barrier'.⁹¹⁹ In their study of the legal consciousness of relatives of adult patients with reduced consciousness, Halliday et al⁹²⁰ connect both their 'law as a shield' and 'law as a sword' schema to Ewick and Silbey's 'before the law'.⁹²¹ Relatives interviewed see the power of law as a weapon (a sword) 'of justice to counteract and call to account the failings of the medical system'⁹²² which the authors situate within Ewick and Silbey's 'before the law' schema.⁹²³ Halliday et al's 'shield' metaphor also fits within the 'before the law' schema, as despite their frustrations at the slowness of the law, relatives respect its role as an impartial and powerful force, acting as a shield and 'protecting society from reckless decision-making about the ending of lives'.⁹²⁴ As within the 'before the law' schema the law as a shield 'deserves respect and compliance from deferential participants'.⁹²⁵

⁹¹⁹ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74, p.69

⁹²⁰ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74

⁹²¹ *Ibid*, p.70

⁹²² *Ibid*

⁹²³ *Ibid*, p.71

⁹²⁴ *Ibid*

⁹²⁵ *Ibid*

Halliday et al also see their metaphor of 'law as a sword' fitting within Ewick and Silbeys' 'with the law' narrative.⁹²⁶ An example is given of one relative interviewed (Tracy) who is described as seeing law disconnected from justice and portrayed just as a resource that can be used for personal gain. Halliday et al comment:

'In the midst of a harrowing and lengthy struggle with a powerful medical system, it is not hard to imagine such a narrative of legality being invoked'.⁹²⁷

Their schema of 'law as a barrier,' fits, Halliday et al suggests, into Ewick and Silbey's 'against the law' schema, both having at their core struggle and resistance against the power of law.⁹²⁸

Halliday et al developed legal consciousness theory from Ewick and Silbey's schema by identifying a gap in their schema and adding a fourth dimension of legal consciousness, which they call 'Collective Dissent'.⁹²⁹ Halliday et al characterise those who express 'collective dissent' as seeing state law as 'illegitimate and oppressive' but being 'resisted and subverted in [their] collective effort to alter the power structures that legality imposes'.⁹³⁰ They use this dimension of legal consciousness when describing participants in their study who have ended the life of their family member. The family members have done this despite the act being unlawful because they believe they are acting in their loved one's best interests, and see themselves as trying to escape the power of the law.⁹³¹ Parallels can therefore be seen in the way in which Halliday et al and Harding both focus on resistance as they develop legal

⁹²⁶ Ibid, p. 72

⁹²⁷ Ibid

⁹²⁸ Ibid. p. 71

⁹²⁹ Ibid, p.72

⁹³⁰ Ibid, p. 70

⁹³¹ Ibid, p. 137

consciousness scholarship. Echoes can be seen here with the Cuttini et al study,⁹³² mentioned in chapter four,⁹³³ of doctors' neonatal decision-making across Europe. In that study doctors seemed to collectively avoid or resist the law in their jurisdiction by making decisions based on factors such as the doctors' religion, rather than the law.

In their study, Halliday et al argued collective dissent also manifests as an act 'to change the power of law in this domain for the benefit of all those who may have suffered similarly'.⁹³⁴ Mention was made in chapter three⁹³⁵ of the participants in this study's express hope that this thesis may bring their concerns about best interest decisions into the open. This wish or indeed, even agreeing to participate in this research, could in the context of a closed profession, be perceived as an act of collective dissent on the part of the doctors involved if the doctors were shown to have similar motivations for taking part in this study. Doctors' resistance to law collectively and individually is a strong theme in the rest of this thesis.

9. Parallels between Halliday et al's study and this thesis

Parallels between this study and Halliday et al's⁹³⁶ can be discerned. Both study the legal consciousness of groups who can be said to have power over another group whose legal consciousness would be exceptionally difficult to study. Halliday et al study the legal consciousness of relatives of patients with

⁹³² Cuttini, M., Nadai, M., Kaminski, M., Hansen, G. De Leeuw, R., Lenoir, S, Lenard, HG (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries, *The Lancet*, 355(9221), 2112-2118

⁹³³ Chapter four, para 4, p.146

⁹³⁴ Ibid

⁹³⁵ Chapter one, para 5.2, pp.17-18

⁹³⁶ Halliday, S, Kitinger, C, Kitinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74

reduced consciousness, rather than the legal consciousness of the patients. Here, doctors making the best interest decisions are studied rather than the disabled children. In both studies the patients' severe cognitive impairment in most cases, and/or severe communication difficulties⁹³⁷ would make the study exceptionally difficult. In both studies, while the primary actors, in Halliday et al's study the relatives and in this study the doctors, are the main focus, the patients with reduced consciousness or disabled children are ever present, being those most affected by the primary actors' legal consciousness.

There are other parallels, too. Both studies are concerned with best interest decision-making; both concern medics and their attitudes and behaviours towards exceptionally marginalized and vulnerable patients and their families. Both are concerned with the interplay between the courts and the medical profession. Both studies have authors with personal as well as academic interests in the subject⁹³⁸ and the empirical research for both studies was conducted broadly at the same time.⁹³⁹ Although different laws apply to best interest decisions for disabled adults⁹⁴⁰ than to children, the data was collected during a similar time period, when societal and medical attitudes towards severely disabled individuals were the same. This thesis can also be seen as pushing beyond Halliday et al's study by exploring the legal consciousness of doctors, who at times seem to be the elephant in the room in their study.

⁹³⁷ In the case of the adults who are conscious at all.

⁹³⁸ Celia and Jenny Kitzinger's sister Polly lives in a reduced consciousness state following a car accident.

⁹³⁹ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74, p. 60

⁹⁴⁰ The Mental Capacity Act 2005 applies to individuals from the age of 16, see s.2 (5) (b) in England and Wales s.64 (4). This requires all decisions for those who lack capacity to be made in their best interests s.4. Adults with Incapacity (Scotland) Act 2000 applies to individuals from the age of 16 in Scotland see s.1 (6). Any intervention must benefit the individual concerned s.1 (2)

The similarities between the two studies make the schema developed by Halliday et al⁹⁴¹ particularly helpful to this study, so are used here, with Ewick & Silbey's⁹⁴² and Harding's⁹⁴³ to explore the legal consciousness of the doctors. Consideration will also be given as to whether existing schema are sufficient or whether the doctors seem to exhibit any expressions of legal consciousness not described in previous studies.

10. Situating the doctors

It was suggested at the beginning of this chapter that the situation of the actors in legal consciousness studies is important. Some consideration is therefore now given to where the doctors in this thesis are situated epistemologically.

First, the doctors are situated firmly within a normative legal framework which can be found in their professional ethical guidance and the jurisprudence of the English court, as was explored earlier. Doctors' status as NHS employees and hence subject to the framework of rights pursuant to the HRA and UN human rights treaties is also significant here.

Secondly, the doctors are also situated firmly in the culture of medicine; the culture of paediatrics and the culture of the NHS. An understanding of culture is therefore important to be able to analyse the doctors' legal consciousness.

Culture can be defined as:

‘the framework of beliefs, expressive symbols, and values in terms of which individuals define their world, express their feelings, and make

⁹⁴¹ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74

⁹⁴² Ewick, P, Silbey, SS, (1992) Conformity, Contestation and Resistance: An Account of Legal Consciousness, *New Eng. L. Rev*, Vol. 26, at p. 731; Ewick, P, Silbey, SS, (1998) *The Common Place of Law, Stories from everyday life*, The University of Chicago Press, Chicago & Ewick, P, Silbey, SS (1999) Common Knowledge and Ideological Critique, *Law and Society Rev*, 33, 1027

⁹⁴³ Harding, R, (2010) *Regulating Sexuality: Legal Consciousness in lesbian and gay lives*, Routledge, Abingdon

their judgments...it is the fabric of meaning in terms of which human beings interpret their experience and guide their actions.⁹⁴⁴

Culture within healthcare is a much-discussed phenomenon. Its importance in the context of doctors' attitudes towards disabled patients was seen in chapter two.⁹⁴⁵ It featured prominently in high profile inquiries into when things have gone badly wrong within the NHS, most notably Bristol.⁹⁴⁶ It was deemed crucial in the events that led to the The Mid Staffordshire NHS Foundation Trust Public Inquiry,⁹⁴⁷ ('Mid-Staffs) published after the timeline of chapter two. The reports of these inquiries included a whole chapter each on culture, so significant was it deemed to be. Both also, helpfully, defined culture in the context of the NHS and medical care.

Bristol defined culture as 'the attitudes assumptions and values of the NHS and its many professional groups'.⁹⁴⁸ It also identified the NHS historic status as a 'national icon' as an 'influence of great importance' on NHS culture.⁹⁴⁹ Further, it recognised a cultural tendency for health professionals to 'withdraw into a kind of professional bunker and view everything outside as a threat'.⁹⁵⁰ Perhaps of particular significance to this thesis, is the 'co-existence of competing

⁹⁴⁴ Geertz, C, (1973) *'The Interpretation of Cultures'*, Basic Books, New York

⁹⁴⁵ Chapter two, para 8, p.75-79 & para 10, p.82-91

⁹⁴⁶ The Bristol Royal Infirmary Inquiry (2001), *The Inquiry into the management of care of children receiving complex heart surgery at the Bristol Royal Infirmary, Final Report*, Bristol Royal Infirmary Inquiry, chapter 22

⁹⁴⁷ The Mid-Staffordshire NHS Foundation Trust Public Inquiry (2013), *Report of the Mid-Staffordshire NHS Foundation Trust Public Inquiry*, volume 3, HC898-111, The Stationery Office, London

⁹⁴⁸ The Bristol Royal Infirmary Inquiry (2001), *The Inquiry into the management of care of children receiving complex heart surgery at the Bristol Royal Infirmary, Final Report*, Bristol Royal Infirmary Inquiry, chapter 22, para 1

⁹⁴⁹ *Ibid*, para. 6

⁹⁵⁰ *Ibid*

cultures⁹⁵¹ Bristol talks of competing nursing, medical and managerial cultures 'so distinct and internally close-knit that the word 'tribe' and 'tribalism'⁹⁵² is used, but these 'tribes' can be, as has already been seen, sub-divided, for example into paediatric sub-specialities or between hardliners and softliners.⁹⁵³

The Mid-Staffs definition of culture, drawing from Vincent⁹⁵⁴ as 'how we do things around here', with 'here' being 'anything from a small group or team, to a whole organisation, a profession or a health system'⁹⁵⁵ captures exactly the complexity of interrelating cultures, which contribute to the framework within which the doctors in this thesis are situated.

The Mid-Staffs report quoting from Vincent,⁹⁵⁶ identified organisational cultures as having key formal characteristics; (i) shared basic assumptions; (ii) discovery, creation or development of those assumptions by a defined group; (iii) group learning of how to cope with its problem of external adaptation and internal integration; (iv) identification of ways that have worked well enough to be considered valid and (v) teaching new members of the group the correct way to perceive, think and feel in relation to any problem.⁹⁵⁷

⁹⁵¹ Ibid, para 9

⁹⁵² Ibid, para 6

⁹⁵³ Chapter six, para 7.2.1, pp. 268-274

⁹⁵⁴ Vincent, C, (2010), *Patient Safety*, 2nd Edition, BMJ Books

⁹⁵⁵ The Mid-Staffordshire NHS Foundation Trust Public Inquiry (2013), *Report of the Mid-Staffordshire NHS Foundation Trust Public Inquiry*, volume 3, HC898-111, The Stationery Office, London, p.1358, para 20.5

⁹⁵⁶ Vincent C, (2010), *Patient Safety*, 2nd Edition, BMJ Books, p.272

⁹⁵⁷ The Mid-Staffordshire NHS Foundation Trust Public Inquiry (2013), *Report of the Mid-Staffordshire NHS Foundation Trust Public Inquiry*, volume 3, HC898-111, The Stationery Office, London, p.1357-8, para 20.5

The doctors in this study can therefore be seen to exist in a complex sea of professional cultures, some complimenting and others contradicting each other. However, those cultures do not exist in a vacuum. The doctors will also bring a particular culture from their education, both their medical education and childhood education. The doctors will also be operating in a multitude of additional cultures personal to them, their faith, their politics, their region and many other factors all of which contributes towards their individual or group legal consciousness. The professional and personal data collected about the doctors and presented in chapter four, helped to give an indication of just some of the multiple factors that impact on each individual doctor, and on every group to which that doctor belongs; these help us to understand individual and group legal consciousness.

11. **How legal consciousness theory helps in an understanding of paediatricians' best interest decisions and how this thesis contributes to legal consciousness scholarship**

To conclude this chapter, how legal consciousness theory aids an understanding of paediatricians' best interest decisions for disabled children, and what this thesis adds to legal consciousness scholarship, will now be summarised.

11.1 How legal consciousness helps in an understanding of best interest decisions

Legal consciousness is a particularly appropriate theoretical framework to apply to an examination of doctors' best interest decision-making, because, as was seen earlier, legal consciousness can be both individual and a 'collective phenomenon'.⁹⁵⁸ As has already been seen in part two, some of the doctors in this study reported acting individually, while others reported acting collectively.

⁹⁵⁸ Chapter seven, para 3, p.295

Moreover, the argument has long been made that medical training is a process of socializing a medical student into the world of medicine.⁹⁵⁹ Medicine is framed as being very much about learning through social interaction. Basnett's⁹⁶⁰ work, as was seen,⁹⁶¹ suggests that this transmission of attitudes in healthcare is particularly important in relation to the treatment and care of disabled adults.

Legal consciousness theory is also adopted in this thesis because it so effectively shines a light on the unique situation of the doctors, acting in a quasi-judicial way, but not being lawyers. In essence, legal consciousness enables this thesis to test further Kennedy's⁹⁶² hypothesis and explore whether, as Kennedy claimed, doctors are making legal and ethical decisions they are not trained or competent to make. It offers a new lens through which to study how the doctors construct best interest decisions for disabled children.

Finally, the importance of relationships to best interest decision-making was seen in chapter six.⁹⁶³ Legal consciousness theory helps show the importance of relationships between doctors and others and how these relationships create and construct law.

⁹⁵⁹ See for example: Harter, LM, Kirby, EL (2004) Socializing medical students in an era of managed care: The ideological significance of standardized and virtual patients. *Communication Studies*, 55(1), 48-67; Jefferys, M, Elston, MA, (1989) The medical school as a social organization, *Medical education*, 23(3), 242-251; Harter, LM, Krone, K J (2001) Exploring the emergent identities of future physicians: Toward an understanding of the ideological socialization of osteopathic medical students. *Southern Journal of Communication*, 67(1), 66-83; and Baszanger, I, (1985) Professional socialization and social control: From medical students to general practitioners, *Social Science & Medicine*, 20(2), 133-143

⁹⁶⁰ Basnett, I, (2001) 'Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467

⁹⁶¹ Chapter two, para 10, pp.82-91

⁹⁶² Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, Published in an amended form in Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

⁹⁶³ Chapter six, para 7, pp.261-282

11.2 What this thesis adds to legal consciousness scholarship

This thesis builds on existing legal consciousness scholarship by studying the legal consciousness of an elite group⁹⁶⁴ of non-lawyers taking legal and ethical decisions, and arguably acting in a quasi-judicial role.

This unique status brings some important new insights to legal consciousness scholarship. First, the stark and extreme nature of the decisions the doctors are taking, namely decisions whether a child lives or dies, brings a new emphasis on the importance of knowing whether and how law is being created in these informal ways. As mentioned earlier, when law is created in this way, the normal checks and balances⁹⁶⁵ in place when law is formally created are not present, so it is important to know what is going on to ensure the rights of society's vulnerable citizens are not overlooked.

Secondly, the doctors' situation also emphasizes the link between law as conceived by legal consciousness scholars and law as it appears 'in the books'. This connection was perhaps less clear previously with scholars such as Mezey⁹⁶⁶ questioning how every day activities could be conceived in any way as law. However, doctors best interest decisions are clearly part of doctors' every day clinical activities, but can also be seen as legal in nature, making it easier to understand how discussions and interactions and other every day activities, or lack of them, can and do create law.

A third contribution that this study makes to legal conscious scholarship is in the way that the doctors' elite status brings focus to the fact that legal

⁹⁶⁴ Medical professionals are classified as being within class 1, the highest of eight classes in the UK National Office for statistics socio-economic classification <http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/guide-method/classifications/current-standard-classifications/soc2010/soc2010-volume-3-ns-sec--rebased-on-soc2010--user-manual/index.html>, accessed 1 May 2017

⁹⁶⁵ see for example Williams A, (1998) *UK Government and Politics*, Heinemann, London, p.9

⁹⁶⁶ Mezey, N (2001) Out of the ordinary: law, power, culture, and the commonplace, *Law & Social Inquiry*, 26(1), 145-167

consciousness theory is about the participant's perceptions of their situation, not the perceptions of those outside the group, which can be different. It is therefore possible that a group of individuals who, to the outside world appears to be elite and confident, perceives itself as vulnerable. It is this self-perception which tells us something about their legal consciousness.

A final contribution this thesis makes to legal consciousness theory is to propose an additional schema of legal consciousness, '**law as kudos**', described by doctors in this study but not found in existing legal consciousness scholarship. This new schema and the reason for it is explained in chapter nine.⁹⁶⁷ In essence, however, it builds on existing schema suggested by Ewick and Silbey, Harding and Halliday et al, capturing a sense of law giving power and enhanced status to a non-lawyer but elite individuals or groups.

This thesis now turns to explore the part played by law in the doctors' decisions, through the lens of legal consciousness. In chapter eight, data from the doctors' surveys are drawn on and in chapter nine, from their interviews. As will be explained, there are limits to how much an individual or group's legal consciousness can be explored using survey data. Accordingly, legal consciousness is used with a light touch in chapter eight, but in more depth in chapter nine. Research question three is answered in both chapters eight and nine. Research question four is also answered in both chapters, but for the reasons just explained, mainly in chapter nine.

⁹⁶⁷ Chapter nine, para 3.1, pp. 363-365

Chapter Eight

What the doctors said (or did not say) about law, rights and ethics in their surveys

1. Introduction

This chapter explores and analyses, using legal consciousness theory, what doctors said in their surveys about law, rights and ethics. What they said in their interviews is explored in the next chapter. The purpose of this exploration and analysis, is to gain a greater understanding of how, if at all, doctors draw on law, in their best interest decisions and what this reveals about doctors' legal consciousness. As was seen in chapter seven,⁹⁶⁸ what people don't say and their accepted ways of doing things can also reveal important aspects of their legal consciousness. Where relevant, what doctors did not say about law for example, if doctors did not mention a child's rights or refer to best interests in circumstance where these concepts might be mentioned, will therefore also be examined.

To help analyse what the doctors either said or did not say about law as was explained in the last chapter, legal consciousness schema developed by Ewick and Silbey,⁹⁶⁹ Harding⁹⁷⁰ and Halliday et al⁹⁷¹ will be used.

The doctors were asked questions in the survey specifically about law, rights and ethics. These were asked in the second half of the survey after the doctors

⁹⁶⁸ Chapter seven, para 4, pp.297-298

⁹⁶⁹ Ewick,P, Silbey, SS, (1998) *The Common Place of Law, Stories from everyday life*, The University of Chicago Press, Chicago, p. 74

⁹⁷⁰ Harding, R, (2010) *Regulating Sexuality: Legal Consciousness in lesbian and gay lives*, Routledge, Abingdon

⁹⁷¹ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74

had answered questions about making difficult decisions.⁹⁷² The placing of these questions at the end of the survey was deliberate, so that the doctors' unprompted observations about law, as they reflected on their decision-making, could be captured in the first half of the survey. Where appropriate, those observations will be drawn on in this chapter.

Mention is made in this chapter of both law and ethics although it is law and the doctors' legal consciousness which is the main focus of this study. As will be seen, while the hardliner doctors tended to talk more about law, the softliner doctors tended to talk more about ethics. Ethics was addressed in the survey in addition to law, because outside of this thesis, law and ethics are grouped together by the medical community, with no clear distinction being made. The RCPCH, for example has an ethics and law committee.⁹⁷³ RCPCH 2015⁹⁷⁴ in essence, guides paediatricians that ethical best interest decisions mean following the law, with the jurisprudence of the English High Court being cited in the guidance.

As was seen in chapter one,⁹⁷⁵ the term ethics is not, within this thesis, conceived within a traditional academic or disciplinary way, but rather through the lens of the doctors' professional practice and guidance from the paediatrician's professional bodies; most notably the RCPCH and GMC. Neither the term 'law' nor 'ethics' were defined in the survey or the accompanying email sent to the doctors, but left for the doctors to define. It was felt that how a doctor, for example, defined 'law' could give an important insight,

⁹⁷² See Appendix 4, pp.427-433

⁹⁷³ <https://www.rcpch.ac.uk/what-we-do/ethics/ethics-and-law-resources/ethics-and-law-resource> accessed 26 January 2018

⁹⁷⁴ Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J, (2015) 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice', *Archives of Disease in Childhood*, 100, s1-s23

⁹⁷⁵ Chapter one, para 2.5, p.6

into how the doctor understood law. Did a doctor, for example, not mention law, or did he or she talk about law as a framework within which he or she worked; did the doctor seem to have a broad view of a spectrum of law relevant to disabled children's healthcare, or did the doctor discuss law in terms of litigation, even just in terms of criminal litigation?

It is recognised that from the short answers given in the survey, it is difficult to gain any real insights into doctors' legal consciousness, but suggestions as to what it might be, taking the survey as a whole, might be gleaned. For example, generally there is a sense that for most doctors, law only meant litigation, although a minority did talk about it more widely in terms of a framework within which they worked. There are also some interesting apparent contradictions. For example, thirty doctors (90%) responded to an explicit question about whether they consciously consider a child's rights stating they did. However, not a single doctor had listed the child's rights as one of the main factors he or she considers when making difficult decisions, when asked to list these factors earlier in the survey. The doctors did, as was seen in chapter four,⁹⁷⁶ list non-clinical factors, such as whether a child attends school or is happy, and even legal factors⁹⁷⁷ but none expressly mentioned the child's rights. One possible reading of this contradiction is that doctors know they *should* consider the child's rights and so say they do when prompted, but they do not consider it to be a 'main factor'. It is perhaps not something at the forefront of their minds when thinking about difficult decisions and therefore not included in their responses to the earlier question. Another possibility is that the doctors *do* consider the child's rights, but use different language from 'rights.' However, when the doctors' words are examined, it is difficult to find any that could be understood as meaning a child's rights.

⁹⁷⁶ Chapter four, para 6.3, pp.137-179

⁹⁷⁷ Chapter four, para 6.3 p.177

In chapter seven,⁹⁷⁸ it was seen how different aspects of an individual life, both professional and personal, contribute and interact to help construct an individual's legal consciousness. But, as was also seen, this is a two-way process, with the group impacting on the individual's legal consciousness and the individual impacting on the group's.

It is possible to imagine that a doctors' legal consciousness will influence the extent to which a doctor is motivated to study law and that studying law will impact on a doctor's legal consciousness. With this in mind,, this chapter first explores the doctors' training and education in law and ethics to see, as far as the limited data allows, whether there are indications that studying law has an impact on doctors' best interest decision-making and legal consciousness and if so how? This will also test Kennedy's argument⁹⁷⁹ that doctors do not have the training and education in law and ethics needed, to make best interest decisions.

Having considered what the doctors said about any training or education in law and ethics, the chapter will then turn to what the doctors said in their survey about specific legal issues. An overview will be given of what the doctors said about seeking legal advice; the threat of litigation; and the importance of law and ethics to their decisions. It is important to include this overview of the doctors' survey responses to capture a broader range of factors that frame and inform doctors' decision making and, also to give some indication of the extent to which the views expressed by the doctors later interviewed, presented in the next chapter, are representative of the wider pool of doctors in this study.

⁹⁷⁸ Chapter seven, para 3, pp. 291-297

⁹⁷⁹ Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, Published in an amended form in Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

To help in an understanding of the impact, if any, of legal/ethical education, the doctors will be classed into three groups according to how much education and training a doctor has received in total, as a medical student and qualified doctor combined. The three groups are (i) doctors who have received no training or education;⁹⁸⁰ (ii) doctors who have had minimal, for example, attended single events or describe their training in ways that suggest it was minimal and (iii) doctors who have had significant training or education. This last group consists of doctors who have either, as under or postgraduates, followed complete courses in law and ethics. These findings will then be mapped to data presented in chapter five,⁹⁸¹ which explored the weight doctors put on prognosis; fertility; quality of life and the child's cognitive ability when making best interest decisions. The aim will be, using these factors as a snapshot, to see whether doctors who have received significant legal/ethical education approach best interest decisions the same or differently from doctors who have minimal or no education; and as far as possible, with the limited data available, to explore what these similarities and differences seem to be.

As mentioned at the end of chapter seven, whilst existing legal consciousness schema will be adopted, for the analysis in this chapter of the survey data, only suggestions and hints of legal consciousness will be sought, recognizing that too little information is available in the survey to draw any firm conclusions about individual or group legal consciousness.

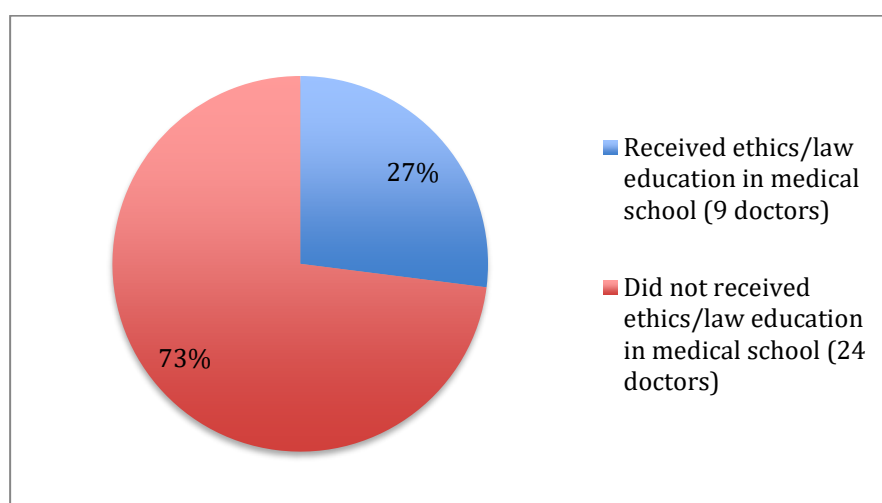
⁹⁸⁰ This means they have attended no courses, workshops, training events, CPD seminars, lectures, tutorials, talks, or similar and not undertaken any on-line or distance training or education.

⁹⁸¹ Kennedy, I, (1979). *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London, Published in an amended form in Kennedy, I, (2001) *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford, pp 19-31

2. Prevalence of training and education in law, rights and ethics

Kennedy⁹⁴⁸ argued almost forty years ago that doctors were making decisions that were essentially legal and ethical decisions, while having no education or training in law or ethics. Kennedy's assertion that the doctors do not have the education and training to undertake this task, seems, for the doctors in this study, largely to be borne out. Just nine doctors (27%) reported having had some education in law, rights or ethics while at medical school. (See figure 58) For all but two of these doctors (6%), this seems, by the doctors' own accounts to have been minimal, for example, a single lecture. Two doctors (6%) described following longer courses in what the doctors called 'medical jurisprudence'. The remaining twenty-four doctors (73%) reported having had no training or education in law, rights or ethics whilst at medical school. It is possible that with the passage of time some doctors may have forgotten whether they had any training or education in law or ethics. It is noteworthy that the two doctors who report having the most education and training in law, rights and ethics, while at medical school trained in Europe⁹⁸² and Scotland, not England, where the majority of doctors in this study were located.

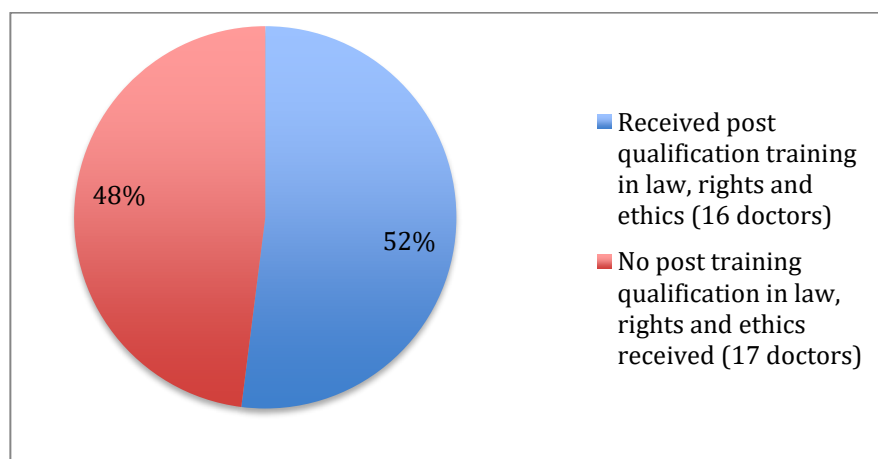
Figure 58: Legal and ethical education while at medical school



⁹⁸² Country not named as this may reveal the doctors' identity

The doctors were also asked about any training in law, rights and ethics they had undertaken since qualification, as figure 59 illustrates. Seventeen doctors (52%) reported that they had undertaken no training or education in law, rights or ethics since qualifying as a doctor.

Figure 59: Post-qualification legal and ethical training



This suggests that sixteen doctors (48%) received no training at all, pre-or post-qualification, in law, rights and ethics. The remaining seventeen doctors (52%) described having undertaken some education. This varied from three doctors (9%) who reported studying for a masters' degree in medical law and one (6%) who followed what she described as 'master level' modules, to doctors who described their training and education in law as 'minimal'. It is perhaps noteworthy, here, that the doctors who were later interviewed, who had undertaken post-graduate studies in law and ethics, all said they had sought out training due to their interest in law and a sense that knowing more was important for their work. No doctor was offered any training in law, rights or ethics as part of their compulsory or discretionary continuing professional education.

It is noticeable that all nine doctors who had some training or education while at medical school, even if this was minimal, chose to undertake some further studies in law once qualified. A possible explanation for this is that even limited exposure to law and ethics while at medical school sparked the doctors' interest

and awareness of the relevance of law and ethics to their work. What is unknown from the limited data available, is why the doctors thought further education in law and ethics was important. For example, it is possible, that doctors sought out legal or ethical education because they saw law as a 'sword'⁹⁸³ and felt the need to arm themselves, so to speak, to enable them to challenge decisions and to address a power imbalance where perhaps they perceive themselves as vulnerable. Alternatively, it could be because the doctors saw law as a 'shield'⁹⁸⁴ and sought either to protect themselves or their child patients, or indeed both. The doctors may have sought an understanding of due process, so that they can defer to the law, lifting the burden, to an extent, on them of having to make life or death decisions, in keeping with Ewick and Silbey's 'before the law schema'.⁹⁸⁵

As seen above, when undergraduate and post graduate training and education is combined, sixteen doctors (49%) reported no education or training in law or ethics at all. Nine doctors (27%) reported minimal and eight (24%) reported having had significant, for example, having followed a course in law and ethics at either under or post graduate stage of training.⁹⁸⁶

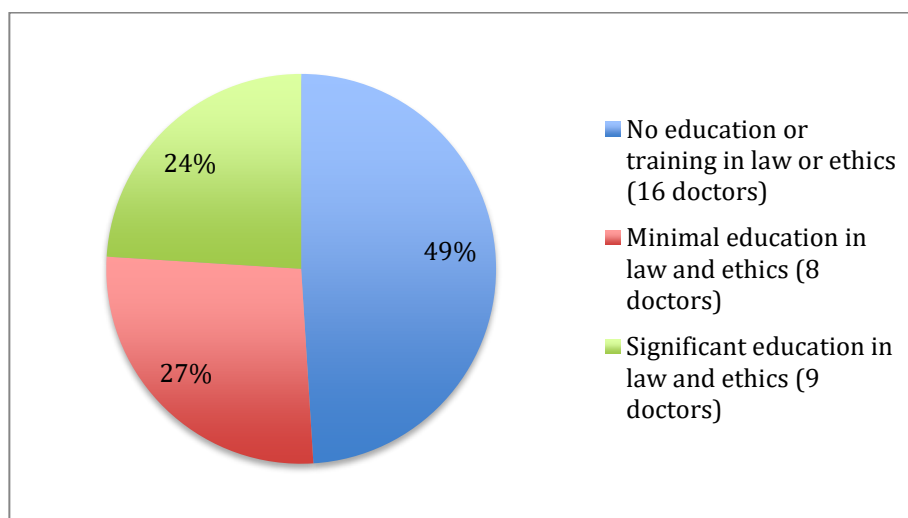
⁹⁸³ Halliday S, Kitzinger C, Kitzinger J, (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74, p.63-64

⁹⁸⁴ Halliday S, Kitzinger C, Kitzinger J, (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74,p.65

⁹⁸⁵ Ewick P, Silbey SS, (1992), Conformity, Contestation and Resistance: An Account of Legal Consciousness, *New England Law Review*, vol 26 & Ewick P, Silbey SS, (1999), Common Knowledge and Ideological Critique, *Law and Society Rev*, 33, 1027

⁹⁸⁶ Although when explored further with doctors at interview it transpired that often these courses were limited to four or six week, one day a week courses, not a full masters course as doctors had suggested in their survey responses.

Figure 60: Education in law and ethics doctors have received pre & post qualification



This suggests that nearly 40 years on, Kennedy's concern that doctors have no training in law, rights and ethics remains a concern. It is important to remember that the doctors in this study were, all but one, consultants who qualified in various years between the 1960s until 1998. The data does show that the 1990s qualifiers received more legal and ethical education than doctors who qualified in earlier decades. Five 1990s qualifiers (71%) reported undertaking significant legal and ethical training (and none reporting no legal or ethical training) compared with two 1980s qualifiers (10%) and one 1970s qualifier (20%), as figure 61 illustrates. However, what this study does find is that almost half the doctors who participated, doctors from across the UK and making best interests decisions day-to-day, have received no formal training or education at all in law and ethics.⁹⁸⁷

What is also of interest, is the doctors' confirmation they have not received training in rights. This is despite the UK government giving undertakings to the Committee of the UNCRC that professionals who work with children in the UK

⁹⁸⁷ The doctors interviewed all said they thought this was representative of paediatric consultants generally. The consensus was that in most tertiary hospitals there was probably one, perhaps two PICU consultants who had some training and education in law and ethics and then the odd consultant here and there from other sub-specialisms who had a particular interest. Training in rights was reported to be even less common.

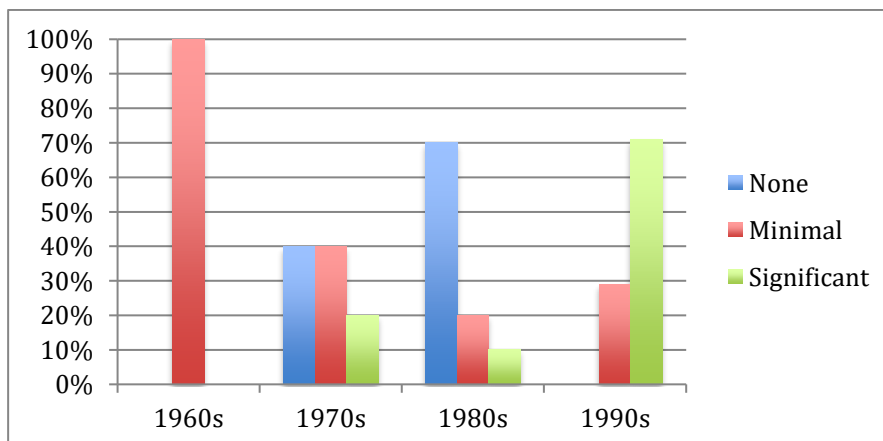
receive training in UNCRC rights.⁹⁸⁸ Doctors may be aware of the rights of the children in their care in other ways than direct education or training, but without formal education and training, the quality and indeed, the accuracy of that training, is hard to assess. The UNCRC is briefly referenced in RCPCH 2015:

‘The United Nations Convention on the Rights of the Child (UNCRC) applies to all children and young people under the age of 18 and was ratified by the UK in 1991. Whilst it cannot be directly applied in UK courts, ratification means that the UK government is bound to honour it and to make all laws, policy and practice applying to children compatible with it.’⁹⁸⁹

However, this statement is only helpful if doctors firstly read it and secondly are aware of the rights that the UNCRC aims to uphold. It is unclear how likely a doctor would be to read the UNCRC without further enlightenment of its relevance to best interest decision making.

Figure 61: Education and training in law and ethic received by decade of qualification

Presented as a percentage of doctors qualifying in each decade
1960s (1 doctor); 1970s (5 doctors); 1980s (20 doctors); 1990s (7 doctors)



⁹⁸⁸ UNCRC (2008) *Committee on the Right of the Child, Consideration of Reports Submitted by State Parties Under Article 44 of the Convention, third and fourth periodic reports of States parties due in 2007 United Kingdom of Great Britain and Northern Ireland, UN, Geneva, para 64*

⁹⁸⁹ Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice, *Archives of Disease in Childhood* 2015;100:s1-s23, para 2.3.1. B

3. **Mapping whether doctors who have studied law and ethics approach best interest decisions the same or differently from doctors who have not.**

In chapter five,⁹⁹⁰ survey data showing how doctors used prognosis, futility, quality of life and cognitive ability in their difficult decisions for disabled children was presented and analysed. Considerable variation was found between doctors as to how they understood these four factors, both with respect to the weight they put on them and also whether the doctor saw the factors as involving clinical or non-clinical issues. If as argued in this thesis, the best interests test is a legal one, these findings are legally significant, as it suggests there is considerable inconsistency in the way the best interest test is applied, at least amongst the doctors from around the UK in this study. The discussion about roster uncertainty in chapter six,⁹⁹¹ adds weight to this concern.

This chapter will now map the weight the doctors put on the four factors of prognosis, futility, quality of life and a child's cognitive ability when making best interest decisions, to see whether there are any discernible differences in approach to best interest decision making between, in particular, doctors who have had no education in law and ethics and those who have had significant education.

As presented in chapter five, four categories are used to classify the doctors according to the weight the doctor put on each of these four factors. These are (i) doctors who saw the factor as an important one when making best interest decisions for disabled children; (ii) doctors who expressed unease at its use; (iii) doctors who had a mixed view, this included doctors who saw both positives and negatives in the use of the factor in best interest decisions, or saw it was

⁹⁹⁰ Chapter five, pp.181-236

⁹⁹¹ Chapter six, para 3.4, pp.243-244

helpful factor in some circumstances but not in others; and (iv) doctors who did not answer or whose answer could not be classified. Each of the four factors is now considered in turn and analysed using the three levels of doctors' legal education.

3.1 Prognosis, weight and legal/ethical education

All eight doctors (100%) who had studied a significant amount of law and ethics put considerable weight on a child's prognosis, when making best interest decisions, describing it as the most important factor or one of the most important factors. In contrast only five doctors (55%) who had received minimal legal/ethical training and seven doctors (44%) who had received no legal/ethical training did so. For the remaining doctors with minimal legal/ethical training, one doctors (11%) expressed unease at the use of prognosis and three doctors (33%) expressed a mixed view.

For the doctors with no legal training, two doctors (12.5%) expressed unease at the use of a child's prognosis in a best interest decision, five doctors (31%) expressed a mixed view and the remaining two doctors (12.5%) did not answer the question or gave answers where their meaning was unclear.

These results seem to suggest that, at least for doctors in this study, doctors who have studied law and ethics are more inclined to put weight on prognosis as a factor in their decisions than those who have had no legal/ethical education. This of course does not mean that doctors do this because they have studied law, although that is a possibility. It may be that whatever influences doctors to put weight on prognosis, also makes them more likely to study law. Certainly, five doctors (62.5%) who had significant legal/ethical education were PICU consultants (50%) of the PICUs in the study and as was seen in chapter five,⁹⁹² seven PICU consultants (70%) in this study

⁹⁹² Chapter five, para 3.4, p. 186

described prognosis as the most important or one of the most important factors in best interest decisions, compared with, for example, four neurologists (44%). Only one neurologist (11%) and two Other doctors (14%) had undertaken significant legal/ethical studies. It is therefore possible that these findings can be explained by PICU consultants being both more inclined than neurologists and Other Doctors to study law and ethics and to put more weight on prognosis as a factor in their best interest decisions. Dr 17 one of the PICU consultants interviewed talked at some length as to why she studied law and ethics when she became a PICU consultant, as will be seen in the next chapter.

3.2 Futility, weight and legal/ethical education

As was seen earlier in chapter five⁹⁹³ the use of futility in best interest decisions is controversial amongst paediatricians, with a lack of consensus as to its meaning and use. This controversy is perhaps reflected in the more mixed results among doctors who have studied law and ethics, as to the weight to be put on futility, compared with prognosis. Four doctors (50%) who had studied a significant amount of law and ethics put considerable weight on futility when making best interest decisions, describing it as the most important factor or one of the most important factors. This can be contrasted with the three doctors (33.3%) who had received minimal legal/ethical training and three doctors (19%) who had received no legal/ethical training who did so. With this factor, seven doctors (44%) who had not studied law expressed unease at its use in best interest decisions, compared with two doctors (25%) who had studied significant amounts of law and three doctors (33.3%) who had studied minimum law. Two doctors (25%) with significant education expressed a mixed view, as did four doctors (25%) with no legal/ethical education. No doctors with minimal training expressed a mixed view and the remaining doctors did not answer the question or expressed views that could not be classified.

⁹⁹³ Chapter five, para 4, pp. 198-207

The notable findings here are that doctors in this study who have had significant legal/ethical studies seem more inclined to use futility as a factor and those who have not studied law seem more inclined to express unease at its use. Unlike with prognosis, however, there does not seem to be an obvious link with a doctor's sub-specialism. As was seen in chapter five,⁹⁹⁴ there was much less consensus between sub-specialisms as to whether futility should be used. Indeed, if for example, the responses from doctors who have not studied law are examined in more detail, it is found that four neurologists (44%)⁹⁹⁵ had not studied law, but two (22%) expressed unease at the use of futility; one (11%) favoured its use as a factor and the fourth (11%) expressed a mixed viewpoint. Likewise, for the five PICU consultants who had not studied law, three (30%)⁹⁹⁶ expressed unease at its use, but one (10%) favoured its use as a factor and one (10%) did not answer the question. It is not possible to give an answer from the data available, why doctors in this study doctors who have studied significant law seem marginally more inclined to use futility as a factor, where as those who have not studied law seem more inclined to express concerns at it use. However, one possible explanation is that, as was seen in chapters five,⁹⁹⁷ there seems to be some confusion amongst doctors as to what 'futility' means. It is possible that some doctors who have studied law and ethics simply feel more confident that they understand what the term means and so are happier to include it as a factor in their decision-making. However, it might be expected that doctors who had studied significant law and ethics, might have become more aware of the controversial nature of futility and been less inclined, rather than more inclined to use it in their best interest decisions. In short, it appears from the data that studying law may make a difference, but it is not clear why.

⁹⁹⁴ Chapter five, para 4.4, pp.201-202

⁹⁹⁵ As a percentage of neurologists in this study

⁹⁹⁶ As a percentage of PICU consultants in this study

⁹⁹⁷ Chapter five, para 4.1, pp.198-199

3.3 Quality of life, weight and legal/ethical education

Quality of life, as was seen in chapter five, is understood by the doctors in this study in different ways, with some, understanding it more as a clinical evaluation involving factors such as level of pain or the child's state of health and others as more of a non-clinical evaluation considering, for example, whether a child is perceived to be happy or attends school.

Similar numbers of doctors, five (62.5%) with significant legal/ethical education and six (66.6%) with minimum legal/ethical education put weight on quality of life as a factor, in their best interest decisions. Slightly fewer, eight doctors (50%) who had no legal/ethical education put weight on it in their decisions. There was more variation however, when the doctors who are uneasy about quality of life being used as a factor are examined. One doctor (12.5%) with significant legal/ethical education reported unease at the use of quality of life as a factor, compared with three doctors (33.3%) with minimal education in law and two doctors (19%) with no legal/ethical education.

In contrast with prognosis, but in keeping with futility, there does not seem to be any suggestion that these findings can be explained by the fact that PICU consultants are more likely to have significant legal/ethical education than doctors from other sub-specialisms in this study. Looking at the data in more detail: of the doctors with significant legal/ethical education who put great weight on quality of life as a factor, three are PICU consultants, the least likely of the three sub-specialisms to favour the use of quality of life, with five PICU consultants (50%) doing so; one was a neurologist, the most likely sub-specialism to favour the use of quality of life, with seven neurologists (67%) doing so and one was an Other Doctor, with five (57%) putting weight on quality of life as a factor. Indeed, the data here does not seem to suggest any obvious link between a doctor's level of legal/ethical education and the weight he or she put on quality of life as a factor.

3.4 Cognitive ability, weight and legal/ethical education

In contrast to quality of life as a factor, there are noticeable differences in the percentage of doctors who said they put weight on a child's cognitive ability when making best interest decisions, depending on the extent of legal/ethical education received. Four doctors (50%) with significant legal/ethical education said they put weight on a child's cognitive ability compared with two doctors (22%) (2) with minimal education and two doctors (12.5%) with no legal/ethical education. However, no real difference can be seen between the percentage of doctors who expressed unease at the use of a child's cognitive ability as a factor in best interest decisions, according to a doctor's legal/ethical education. Doctors with significant legal/ethical education, make up two (25%) and doctors with minimal legal/ethical education make up a further two (22%) of doctors who expressed unease at the use of a child's cognitive ability as a factor in best interest decisions. A similar number (2) but smaller percentage, (12.5%) of doctors with no legal/ethical education expressed similar unease. Once again there is nothing in the data to suggest that these differences can be explained by the doctor's sub-specialism, when these figures are considered alongside the percentage of doctors from each sub-specialism who either said they put weight on a child's cognitive ability in their best interest decisions or expressed unease at doing so. Doctors in this study who have significant legal/ethical education do seem to approach a child's cognitive ability as a factor differently from those with no legal/ethical education when making best interests decisions. What is unclear from the limited information available in a survey is why? Also, it is acknowledged that the small number of doctors in this study means that it is not possible to claim that these findings are representative of the paediatric population as a whole.

To summarise so far, almost half the doctors in this study (48%, 16 doctors) report having no formal training or education⁹⁹⁸ in law and ethics. The nine

⁹⁹⁸ This means they have attended no courses, workshops, training events, CPD seminars, lectures, tutorials, talks, or similar and not undertaken any on-line or distance training or education.

doctors (27%), who have had significant training in law and ethics, five (55%) of whom were PICU consultants, do seem to use prognosis, futility and a child's cognitive ability differently from doctors who had received no legal/ethical education when making best interest decisions. With each of these factors, doctors with legal/ethical education were more likely to say they put weight on those factors than doctors who had not received any legal/ethical education. This difference was not seen for quality of life, as a factor, although doctors with minimal legal/ethical education did seem more likely to express unease at its use. For prognosis, the difference may be explained by the doctors' sub-specialism. However, this does not seem to explain the difference for the other factors. What is not clear from this data is whether the doctors with more legal/ethical education make their decisions more in keeping with how they are guided to make best interest decisions by their professional ethical guidance and the law –i.e. the jurisprudence of the English High Court. This is however, considered in the next chapter when what the doctors said at interview about law is considered in detail.

It does seem possible to conclude that doctors who have had significant legal/ethical training do approach best interest decisions differently. But what is not clear is whether this is *because* of the doctors' legal/ethical training. It is possible that being exposed to concepts such as 'best interests' or 'futility' during training will make a difference. However, as the doctors were not asked in the survey about the detail of any training, it is not known what the doctors' training covered. Despite this, it seems likely that the doctors do fall within different schema of legal consciousness, but there is insufficient data in a survey to determine how (and again, these numbers are small). An issue also still to be addressed, is whether the doctors' different approaches to best interest decision-making leads to different outcomes for the children at the centre of those decisions. This is something discussed in the next chapter, as one of the themes picked up by doctors in their interviews.

Having mapped what the doctors said about how they made their decisions to the doctors' training and education in law and ethics, this chapter will now turn to a brief overview of what doctors said about the law, rights and ethics in their survey responses.

4. Perceptions of the law

Doctors were asked for their perceptions of the relevance and influence of the law upon their difficult decisions for disabled children. These answers were brief, often too brief to draw significant meaning. However, some answers do give some insight, albeit small, into how the doctors view law in this context.

None of the doctors mentioned the phrase 'best interests' or an obvious proxy when asked directly about law and ethics in the survey. It will be recalled from chapter four,⁹⁹⁹ that four doctors (12%) did, however, list best interests or an obvious proxy, in their initial list of the factors they consider at the start of the survey. A further nine doctors (27%) also cited factors which are important elements of the best interest test.¹⁰⁰⁰ For example, three cited the balancing of benefits and burdens of treatment and six cited consulting widely with other health professionals and the child's parents. For all these doctors, this perhaps suggests that, perhaps unsurprisingly for doctors, for them, best interests is a medical not legal determination. However, the remaining twenty doctors (60.5%) made no reference at all to a child's best interests or clear proxies in any part of their survey.

Fourteen doctors (42%) wrote about the obligation on them not to break the law, several indicating in their answers that, provided they did not break it, the law had no relevance to their difficult decisions. These doctors' answers seem to suggest possibly fear or suspicion of the law, since law was only being

⁹⁹⁹ chapter four, para 4, pp. 178-179

¹⁰⁰⁰ As the test is set out in cases such as *Re J (A Minor) (Wardship: Medical Treatment)* [1991]; 2 WLR 140

mentioned in terms of litigation. This does seem to suggest a perception of the law as distant, intervening when things go wrong, often to punish, perhaps most in keeping with Halliday et al's 'law as a sword' schema.¹⁰⁰¹

Only two survey doctors (6%) (Drs. 2 & 29) described the law as much more than just a mechanism to resolve disputes, in one case drawing expressly and in the other implicitly, on the importance of not discriminating against disabled children. Dr 2 (PICU) for example, wrote "*Law supports the care of the disabled child and underwrites the same rights as all other children*". Relating this back to the impact of training and education, Dr 2 had received no training or education in law and ethics and Dr 29 had received minimal training. This suggests that these two doctors seem to have developed this broader understanding of the law in some other way. Dr 29 did talk about how he developed an understanding of the importance of law at interview as is explored in the next chapter, talking particularly of developing an understanding of child's rights while working under an eminent child psychoanalyst treating children with mental health problems.

Perhaps the lack of nuance in the doctors' answers is unsurprising given their brevity, but the answers do seem to suggest that the doctors in the survey saw law in very narrow terms. As will be seen later in this chapter, twenty doctors (60.5%) reported having had discussions with their trust's legal teams at some point in their career. This seems to suggest that doctors see 'law' as impinging on their working lives, just not as part of the framework of their difficult decisions. which as was seen in chapter four, thirty-one of the doctors (94%) defined as end-of-life decisions whether to withhold or withdraw treatment. Indeed, five doctors (15%) described the law as having no relevance (Drs. 4 (Other), 10 (Other) & 25 (Other) or little relevance (Drs. 30 (neurologist) & 28 (PICU)) to their decisions for disabled children; suggesting an extremely narrow

¹⁰⁰¹ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74

interpretation of the law. Dr 25 (Other) had received minimal legal/ethical education, the other doctors had received none. It is noticeable that all the doctors who described law as having no relevance to best interest decisions were from sub-specialisms other than PICU and neurology, again raising the question not answered here, as to whether the doctors' sub-specialism is significant. One Other Doctor, however, did reference the Disability Discrimination Act,¹⁰⁰² equality and diversity law, and the HRA¹⁰⁰³ indicating a slightly broader perception of the law than other doctors. The doctor reported having received minimal legal/ethical education. The doctor is the parent of a disabled child, which may explain the doctor's awareness of the particular legislation mentioned, although Parsons et al¹⁰⁰⁴ found parents of disabled children did not necessarily have awareness of disability legislation. The doctor can perhaps be seen as fitting more within Halliday et al's "law as a shield" schema,¹⁰⁰⁵ providing protection to disabled children.

5. When do doctors turn to the law?

To try and better understand how doctors conceptualise law when making best interest decisions, they were also asked in the survey, whether they ever sought legal advice when making difficult decisions and if they did in what circumstances?

Twenty doctors (60.5%) said they had consulted with their hospital's lawyers. The doctors cited a range of reasons, some unrelated to end-of-life decisions,

¹⁰⁰² Disability Discrimination Act 2005 c.13

¹⁰⁰³ Human Rights Act 1998 c 42

¹⁰⁰⁴ Parsons, S, Lewis A, Ellins, S, (2009) The views and experiences of parents of children with autistic spectrum disorders about educational provision: comparisons with parents of children with other disabilities from an online survey, *European Journal of Special Education Needs*, vol.24, Issue 1, pp.37-58

¹⁰⁰⁵ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74

for example, child safeguarding. Writing specifically about best interest decision-making, thirteen doctors (39%) cited disagreements with a child's family as the catalyst to them contacting their legal team. It will be recalled from chapter four¹⁰⁰⁶ that nineteen doctors (58%) cited disagreements with parents as the aspect of difficult decisions for disabled children they found most difficult.¹⁰⁰⁷ Four doctors (12%) also mentioned disagreement between health professionals as a reason to contact their legal team. As was also seen in chapter four, twenty-six doctors (78%) reported disagreements with other doctors as to a disabled child's best interests.¹⁰⁰⁸ Suggesting doctors are more likely to frame disagreements with parents as to a child's best interests, than with colleagues as 'legal'.

There are many reasons why a doctor could choose to contact their lawyers when they disagree as to a child's best interests. For example, the doctor could be seeking advice as to how best to ascertain a child's best interests, protecting the child, perhaps showing a 'law as a shield' legal consciousness. This could also be seen as falling within Ewick and Silbey's schema of 'before the law' seeing law as the arbiter of disagreements.¹⁰⁰⁹ Alternatively a doctor could be seeking advice as to whether a proposed course of action is lawful, to safeguard and protect themselves from the law, perhaps seeing law more as a power to be feared, in keeping with a 'law as a sword' legal consciousness.

Dr 13 (Other) did expand a little on her reasons for contacting lawyers, again perhaps expressing a 'before the law' legal consciousness:

¹⁰⁰⁶ Chapter four, para 5.4, p.171-172

¹⁰⁰⁷ Ibid

¹⁰⁰⁸ Ibid

¹⁰⁰⁹ Ewick P, Silbey SS, (1992), *'Conformity, Contestation and Resistance: An Account of Legal Consciousness'*, New England Law Review, vol 26 & Ewick P, Silbey SS, (1999), *'Common Knowledge and Ideological Critique'*, Law and Society Rev, 33, 1027

“When decisions appear to (or could potentially become) controversial or where it is not clear that a decision would be lawful. Where there is disagreement about best interests between clinicians or with families”

Dr 5 (Other) wrote he would refer to his legal team

“When there is disagreement between staff and parents or when potential murder case.”

His answer is ambiguous, it is unclear whether he is meaning a potential murder unrelated to the child’s healthcare (for example a child presenting at hospital with suspicious injuries) or a potential ‘murder’ by healthcare staff and a fear on the part of Dr 5 that he or a colleague may be charged with murder. If this is the case, this could be read as Dr 5 seeing ‘law as a sword’, which is threatening him or his colleagues, or it could also be read as Dr 5 seeing ‘law as a shield’ and seeking its and his legal team’s protection.

The survey data suggest that PICU consultants seem more likely to consult with their Trust’s legal team, with eight PICU consultants (80%) in this study indicating they do. This is perhaps not surprising, as PICU consultants are most likely to be involved in decisions as whether to withdraw or withhold treatment. Moreover, as has been seen in chapter four,¹⁰¹⁰ PICU consultants reported disagreements with parents more commonly than other sub-specialities, which was the most common reason given for contacting a legal team.

Five neurologists (55%) also said they contacted their lawyers. Four Other Doctors (29%) - the oncologist, metabolic specialist and both endocrine consultants in this study - all reported that they did not contact their legal teams.

Having significant legal/ethical education does not seem to influence whether a doctor contacts his or her legal team. Indeed, the same percentage, 62.5% of

¹⁰¹⁰ Ibid

doctors who had significant legal/ethical education (3 doctors) and had no legal/ethical education (10 doctors), reported contacting their legal team for advice. However, it is acknowledged that the small numbers in this study, may be impacting on these percentages.

To summarise what can be concluded about doctors who contact their legal team: disagreements seem to be the main reason contact made. However, it is unclear whether doctors are doing so defensively, fearing litigation, seeing law as a sword, or looking to protect themselves, seeing it as a shield. Alternatively, the doctors may be wanting advice as to how to ascertain a child's best interests, still seeing law as a shield, but this time seeking to protect the child. It is of course possible, that doctors are contacting their legal teams for a combination of reasons.

6. Conclusions

The survey responses of the thirty-three doctors in this study seem to suggest that for almost half the doctors (48%), Kennedy was correct in his assertion that doctors do not have training in law and ethics.

Doctors who have received training in law and ethics do seem to conceptualise their best interest decisions for disabled children differently from doctors who have no legal/ethical training, but whether this is *because* to this training, is unclear. It is also not possible to make a judgment as to whether doctors with legal/ethical education are 'better' at making best interest decisions.

Law for the majority of doctors in this study was seen solely in terms of litigation, i.e. as a threat, or law as a 'sword' within Halliday et al's schema. Doctors who have studied law also seem possibly to fear law – or at least be aware of law and its impact – more so than doctors who have not, but again there is insufficient data to explain why. It is also possible that the

doctors chose to study law, in part, because they feared or felt vulnerable to law's power.

Having explored what the doctors' survey's tell us about how the doctors conceptualise law in relation to their difficult decisions for disabled children, the next chapter now turns to an analysis of the semi-structured interviews with doctors, looking at what these reveal about the part, if any, played by law and ethics in doctors' best interest decisions and the doctors' legal consciousness.

Chapter Nine

What the doctors said (or did not say) about law, rights and ethics in their interviews

1. Introduction

This chapter continues from the last, by exploring what the nine doctors who were interviewed said, and did not say, about law and ethics in their interviews. As was discussed in chapter three,¹⁰¹¹ the interviews with the doctors were semi-structured, allowing each doctor the freedom to discuss the aspects of his or her best interest decisions-making for severely disabled children that was perceived to be the most important. Allowing doctors this freedom helped reveal their legal consciousness, by showing how the doctor constructed and understood best interest decision-making.

At the start of chapter six,¹⁰¹² it was seen that the doctors choose to talk about different aspects of their decision-making and at different length. While some doctors talked at great length about law and ethics others talked more about other aspects of decision making. This led to a diversity in the amount of data collected from each doctor. This is reflected in the extent to which each doctor is discussed in this chapter.

There was considerable variation in the content, tone and language used by the doctors in their interviews. However, while there was considerable variation between the nine doctors, there were commonalities in the tone and language amongst the hardliners and also amongst the softliners, as defined in chapter six.¹⁰¹³ For this reason, when analysing what the doctors said in their interviews, the hardliner and softliner classifications will be used. As a reminder, the

¹⁰¹¹ Chapter three, para 5, p.109

¹⁰¹² Chapter six, para 1, p.237

¹⁰¹³ Chapter six, paras. 7.2.1-7.2.2, pp.268-271

terminology being used refers to the way a doctor approaches best interest decisions, for disabled children. As explained in chapter six,¹⁰¹⁴ softliners are usually, but not always, doctors who work with the child long term, whereas the hardliners tend to be acute specialists called in to treat a child in a crisis. The two camps of doctors tended to use different language. The softliner tended to stress the more positive aspects and the hardliners tended to stress the more negative aspects, when talking potential treatment for a disabled child. Softliners tended to make decisions based on an individual child and consult with others to decide a child's best interests. Hardliners were more likely to use heuristics to guide their decisions and make decisions without wider consultation. For example, hardliners said they would, as a matter of practice, exclude a cognitively impaired child from PICU.

Dr 17 described herself as a hardliner, and so has been classified here as such. The rest of the doctors have been classified based on an overall assessment of their interview and survey responses. This is based on an analysis of the language used and how the doctors described making their best interest decisions for disabled children. As was discussed in chapter six, the distinction between hardliner and softliner doctors is not binary, but rather a spectrum. For example, Dr 17 was on the hard end of the hardliner doctors, although even she at times made comments, which could be labelled softliner in tone. In contrast Dr 24 was on the soft end of the hardliners, expressing views that could put her into both camps, but on balance put her just in the hardliner camp. It is acknowledged that, apart from Dr 17, the categorisation of doctors as hardliners or softliners is based on the subjective assessment of the researcher. The classification of each doctor interviewed is shown in table 62 below, with five of the nine doctors classified as softliners and four as hardliners. Each doctor's level of legal education is also shown.

¹⁰¹⁴ Ibid

It was noted in chapter five¹⁰¹⁵ that PICU consultants and doctors who only saw children acutely, so did not have the opportunity to form long-term relationships with the child and his or her family, were more likely, but not exclusively, to be hardliners. In contrast neurologists and doctors who saw a child routinely, often over many years were more likely to be softliners. Doctors, however, also bring a complex mix of personal and private characteristics to their decisions, not just their sub-specialism and the experience that brings. This means doctors from all three sub-specialisms, PICU doctors, neurologists and Other Doctors are found within both softliner and hardliner classifications. As can also be seen from table 62, the level of a doctor's legal education does not seem to influence whether a doctor is a hardliner or softliner, with doctors with no, minimal and significant legal education found in both camps. Indeed, there was an almost equal spread of doctors within each level of legal education in each camp, amongst the doctors interviewed. For these doctors, whether a doctor was a softliner or a hardliner did not seem to influence whether a doctor contacts his or her legal team, with three hardliners and three softliners saying they did do.

Figure 62: Interviewed doctors' legal education and whether the doctor's responses appear to show a hardliner or softliner approach

Dr	Sub-specialism	Amount of legal/ethical education	Consulted legal team	Hardliner/softliner
1	Neuro	none	yes	soft
7	Neuro	none	no	hard
10	Other (oncology)	none	no	soft
14	Other (respiratory)	none	yes	hard
17	PICU	significant	yes	hard
18	PICU	significant	yes	soft
24	Neuro	minimal	yes	hard
29	Neuro	minimal	yes	soft
32	Other (Palliative care)	none	no	soft

¹⁰¹⁵ Chapter five, para 2, p.183

Clear differences between the hardliner doctors and the softliner doctors were found in their interview discussions. An analysis of the interview transcripts shows that the hardliner doctors used what can be described loosely as legal language - words such as law, best interests, judges and court - far more frequently than the softliner doctors. For example, 'court' is mentioned a total of forty-five times in the interview transcripts, but forty of those times were by the hardliner doctors. Similarly, 'best interests' were mentioned fifteen times in the doctors' discussions, with ten of the references to 'best interests' being made by hardliners. In contrast, the softliners tended to talk about decision-making for disabled children, much more in terms of the relationships between the various parties, seeing, it seems, best interest decision making much more, as series of discussions than a legal process. This also comes across in the vocabulary used. For example, the word 'relationship' was used fifteen times in total, but all but one use of the word was by a softliner doctor. Indeed, Dr 14 the hardliner doctor who did use the word 'relationship,' did so when talking about relationships between doctors and parents breaking down. In contrast, softliners tended to talk about good relationships as key to good best interest decision-making. The word 'discussion' was also used sixty-nine times in the transcripts, but softliners used it more frequently, with forty-four of these references being made by softliners. It is noteworthy also that Dr 17 made fifteen of the twenty-five hardliner references to discussion, with ten of those references being to discussions that had not taken place about end-of-life care, but which in Dr 17's view should have occurred. Throughout their interviews the tone of the hardliners is noticeably negative, when compared with the discussions by softliners. Hardliners talked much more frequently about reasons why a disabled child should *not* have treatment, in contrast to the softliners who tended to emphasise more the positive aspects of a disabled child's life, such as a child's loving relationship with family members or engagement at school.

The differences in language was also seen when in interviews, the doctors picked up the theme of conflict between doctors, particularly with PICU

consultants. For example, Drs 7 & 24 - both hardliner doctors - used legal terminology such as discrimination and prejudice, whereas the softliner doctors raised similar concerns, but did not use legal terminology. For example, Drs 10 and 32- both softliner doctors - talked instead of the PICU consultant's behaviour being *ethically* unacceptable.

The hardliner doctors also referred, without prompting, to legal cases in their discussions more frequently than the softliners. Hardliners made five mentions of legal cases compared with just two by softliners, and even then, the context in which softliners referred to legal cases seemed to be different from the context in which they were mentioned by hardliners. Both Drs.7 and 14 (hardliners) cited the criminal trial of Dr Leonard Arthur,¹⁰¹⁶ discussed in chapter two. Drs 17 and 7 both mentioned, *Airedale N.H.S. Trust v Bland [1993]*.¹⁰¹⁷ Dr 17, a hardliner, also cited the case of *A NHS Trust v MB [2006]*,¹⁰¹⁸ while Dr 10, a softliner, did mention *An NHS Trust v SR [2012]*¹⁰¹⁹ a case involving Neon Roberts, a child with a brain tumour whose mother did not wish him to have radiotherapy. However, the context in which Dr 10 mentioned this case was qualitatively different from the context in which the hardliner doctors cited legal cases. The hardliners, as will be seen, cited cases in the context of discussing law as a negative influence and their own sense of vulnerability before the law. In contrast, Dr 10, an oncologist, cited the Neon Roberts case when discussing disagreements with families, seeming to see law as way of resolving that disagreement, saying he would have applied to the court in similar circumstances. A fear of or anxiety about the law was also seen in the hardliner doctors' responses when specifically asked whether cases involving disabled children impacted on their practice. Drs. 24, 14 and 7, all hardliner doctors, said

¹⁰¹⁶ *R v Arthur*[1981] 12 BMLR 1, heard before Farquharson J, 3-5th November, 1981

¹⁰¹⁷ *Airedale N.H.S. Trust v Bland* [1993] A.C. 789 House of Lords

¹⁰¹⁸ *A NHS Trust v MB* [2006], EWHC 507 (Fam)

¹⁰¹⁹ *An NHS Trust v SR* [2012] EWHC 3842 (Fam)

that their reaction to such cases (and, they added, in their view it would be the reaction of most doctors) or when hearing of any legal cases which might be relevant to their area of medicine, was to think “*there but for the grace of God go I.*” In contrast, three of the five softliner doctors said they were not aware of the legal cases. In addition to Dr 10’s awareness of the Roberts case, Dr 29 was aware of the litigation relating to David Glass,¹⁰²⁰ (discussed in chapter two)¹⁰²¹ but, as shall be seen, rather than expressing a sense of fear for the doctors involved, was critical of the doctors’ treatment of David and said the doctors should have applied to court so that the court could determine what was in David’s best interests.

As was discussed in chapter six,¹⁰²² there also seem to be other qualitative differences in the language used by the hardliners and softliners. This is especially noticeable in the language used when talking about the children at the centre of their decisions and their families. As was seen, the hardliners seemed more likely to speak about the child, or parents, using dismissive language, for example, referring to disabled children as a group as ‘*no hoppers*’ or describing parents as “*selfish*” or “*pathological*”. In contrast, the softliners used more positive language, often expressing compassion. For example, softliner Dr 32 talked about disabled children “*participating in relationships*” and both Dr 1, also a softliner and Dr 32 talked about the children’s lives having “*value*”.

An analysis of the interview transcripts suggest that best interest decisions are conceptualised differently by the hardliner and the softliner doctors, as this chapter will go on to explore in more detail. The interviews with the softliner

¹⁰²⁰ *Glass, R (On the application of) v Portsmouth Hospitals NHS Trust* [1999] EWCA Civ 1914; *Glass, R (On the application of) v Portsmouth Hospitals NHS Trust* [1999] EWHC Admin 343; *Glass v UK* [2003]ECHR Admissibility Decision no. 61827/00

¹⁰²¹ Chapter two, para 7, pp. 61-75

¹⁰²² Chapter six, para 7.2.2 , pp.269-271

doctors will first be analysed, followed by the interviews with the hardliners, to ascertain the role of law, rights and ethics, if any, in their best interest decisions and what the doctors reveal about their legal consciousness. The difference in the amount the softliner and hardliner doctors talk about law is reflected in the way the rest of this chapter is presented. More space is given to an analysis of what was said by the hardliner doctors, with each doctor being individually analysed. In contrast, less space and less individual analysis is given to the softliner doctors, instead the softliners are analysed thematically. This is because the softliners said much less than hardliners directly about law. Therefore, for softliners, it is largely what they did *not* say about law which is of interest, and this first discussed.

2. Softliners

As was mentioned at the start of this chapter, the tone and content of the five softliners doctors' interviews was qualitatively different from the interviews with the four hardliners. The softliners talked much less about law as it is in the books and tended not, in contrast to the hardliner doctors, to use legal language or refer to legislation or case law.

2.1 Perceptions of law

When the softliners did talk about legal cases, as will be seen, this was also qualitatively different from the hardliners' discussions of the legal cases. Like hardliners, softliners seemed to see the court as a distant place of last resort, to which one went, or was taken, in keeping with Ewick and Silbey's schema of 'before the law'.¹⁰²³ However, in contrast to the hardliners, for the softliners, once there, the court seemed to be seen as a helpful place where difficult decisions could be solved, not a threatening place to be feared. It is interesting

¹⁰²³ Ewick P, Silbey SS, (1992), *Conformity, Contestation and Resistance: An Account of Legal Consciousness*, New England Law Review, vol 26 & Ewick P, Silbey SS, (1999), *Common Knowledge and Ideological Critique*, Law and Society Rev, 33, 1027

to note that this seems to fit, as discussed below, with hardliner Dr 14's actual experience of court, rather than his and other hardliners' discussions of their perceptions of the court. Moreover, when softliners talked about going to court there was much more of a sense that the beneficiary of any legal action was the child, with the aim of any court hearing being to provide a shield for the child by determining his or her child's best interests. This seems to contrast with the hardliners' conception of the court as a place to be feared, but also a place of protection, a shield for the doctor, rather than the child.

2.2 Conceptualising and constructing best interests

Although the softliners do not use terminology such as best interests and do not reference the law in the same way as the hardliners, the way in which the softliners discuss and describe their best interest decision-making for severely disabled children does, as was identified in chapter six,¹⁰²⁴ seem to be much closer to the normative conception of how best interest decisions should be made according to the doctors' professional guidance and stream of cases which followed on from *Re B (A Minor)* [1981]¹⁰²⁵ discussed in chapter two.¹⁰²⁶ The softliners described how they make best interest decisions in a way that fits within the normative conception of best interests as one of consulting widely, looking at the individual child's best interests and their wider welfare as well as medical needs. In part, this seems to be because softliners are more likely to be the doctors with long term relationships with families, described in five.¹⁰²⁷ However, the distinction between softliner and hardliner doctors is more nuanced than this. As is seen in figure 62 above, Dr 18 a softliner doctor is a PICU consultant who sees children just acutely and Dr 7 and Dr 24 are both hard liner doctors, (albeit at the softer end of hardliners) but

¹⁰²⁴ Chapter six, pp.237-284

¹⁰²⁵ *Re B (A Minor)* (Wardship, Medical Treatment) [1981], WLR 1421, CA, August 1981,

¹⁰²⁶ Chapter two, para 7.2.2-7.2.3, pp.269-273

¹⁰²⁷ Chapter five, para 2, p.183

neurologists, who have long-term relationships with patients. It seems that, as with a doctors' legal consciousness, many factors interact to create a softliner or hardliner persona.

Relationships do seem to be of central importance to soft liner doctors. Dr 1, for example talked about the need for discussion between all parties, he talked about the importance of maintaining good relationships with a child's parents and stressed the importance of involving nurses, (who he said will often know a child better than a doctor), in discussions. Dr 10 described making difficult decisions in similar terms, putting strong emphasis on the importance of discussion and consultation. Like Dr 1 he stressed the importance of involving the child's parents, where possible the child and also the nursing team in discussions. A common theme amongst all the doctors, as was seen in chapter six,¹⁰²⁸ was disagreements between doctors as to a child's best interests, especially between PICU consultants and non-PICU doctors. As was seen, while some doctors talked of 'keeping quiet' (most noticeably hardliner Dr 14), other doctors, (most noticeably softliners such as Drs 1, and 10) talked of discussion and involving more people in the decision as a way of resolving this conflict. Indeed, Dr 10 said he would get a '*third, fourth, fifth opinion, if necessary*', until consensus is reached. Dr 10 did, as has been mentioned, said he would apply to court '*as a last resort*' citing the case of *An NHS Trust v SR* [2012]¹⁰²⁹ as the sort of circumstances where he would feel this necessary. However, as mentioned, Dr 10's motivation seemed qualitatively different from that of the hardliners who had talked about court applications. Dr 10's motivation seemed to be to ensure the child's best interests are followed, rather than to provide the doctor with a legal shield, as the hardliners seem to

¹⁰²⁸ Chapter six, para 7, pp.261-276

¹⁰²⁹ *An NHS Trust v SR* [2012] EWHC 3842 (Fam)

suggest they are doing. He seems to be using the law as a shield for the child, within Halliday et al's schema.¹⁰³⁰

Dr 32, Dr 1 and Dr 29 as well as hardliner doctors, Dr 24 and Dr 14 were all critical of PICU consultants' treatment of disabled children and all attributed the behaviour of PICU consultants they criticised as being due to PICU consultants' lack of experience of the lives of disabled children, suggesting the importance of the relationship between the PICU consultants and the children and their families in the construction of best interest decisions.

Dr 18 also attributed the behaviour she criticised in her PICU colleagues to the culture of her hospital, or at least its PICU department. Dr 18 attribute her different values from those of her colleagues to having, unlike many of her colleagues, worked in a range of PICU departments within a range of cultures:

"I think some of the problems with some of my colleagues is that they have only trained here, they only see ICU as practiced here and they haven't seen how it can be practiced elsewhere."

The importance of culture on the development of an individual or groups' legal consciousness was discussed in chapter seven.¹⁰³¹ It is possible to see how Dr 18, who had worked in several hospitals, including overseas, had developed a different conception of best interest decisions from that of her colleagues, some of whom had spent their whole career in one hospital.

Both Dr 18 and Dr 32, like the other softliner doctors, but perhaps even more so, stressed the importance of good communication between doctors for good best interest decision-making. Dr 18 talked about the need to involve the whole multi-disciplinary team saying "*there is quite a lot to balance and you have to consider other people's views*". In particular Dr 18 stressed the importance of

¹⁰³⁰ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74

¹⁰³¹ Chapter seven, para 3, p. 295

neurologists being involved when best interest decisions are being made for severely disabled children. Both doctors stressed the importance of including the child in decisions where possible and of parents being fully involved. Dr 18 described parents' views as "*a major influence*" on her best interest decisions.

Both doctors also stressed the importance of good communication between doctors and families. Dr 32 talked of problems arising when doctors avoided communicating with families, especially when they avoided discussing end-of-life planning for children with life limiting and life threatening conditions, something described as a common problem. He spoke of the importance of an advanced care plan.¹⁰³² Although Dr 17, a hardliner, also spoke of the importance of advance care plans, once again there was a qualitative difference in their discussions. While Dr 17 talked about the plans as being important to protect doctors, providing doctors with a shield, Dr 32 talked about advanced care plans being important to provide a shield for the child, ensuring that a child received treatment when it was in his or her best interests, but also did not receive treatment when this route was in the child's best interests.

Mention was made earlier of the qualitative difference in the way the hardliners and softliner doctors spoke about the children. The softliner doctors but particularly Drs 18 and 32 seemed to construct best interests as communication, dialogue between the parties who know the child and the child themselves where possible, emphasising the relational nature of legal consciousness. The importance of valuing the child was particularly noticeable with Dr 32. He spoke about the value he believed severely disabled children bring not just to their families, but also to health professionals and to society in general. He spoke of their '*preciousness*'.

¹⁰³² Advanced care plans for children are not legally binding

2.3 Role of Ethics

Dr 10 mentioned consulting with his clinical ethics committees. He described the experience a very helpful one, assisting him to resolve his practical ethical dilemma. This, as will be seen below, contrasts with hardliner Dr 14's negative experience of clinical ethics committees. What is unclear from Dr 14 and Dr 10's accounts is whether it was the clinical ethics committees at their respective hospitals that were different - for example, one taking a more practical and the other a more theoretical approach - or whether it was the way the two doctors construct the information they are given which was different. Dr 10 certainly seemed to embrace ethics, talking of it as being '*built into us*' as doctors.

Softliner, Dr 1 also mentioned ethics, but described his experience of it as disappointing. He described himself as self-taught, but echoed the concerns, as shall be seen, Dr 14 voiced when talking about ethics committees. Dr 1 said he looked to ethics to provide him with some firm principles for his decision-making, but did not find this by reading about different branches of ethics. This perhaps suggests Dr 1 was seeking but failing to find a framework to support his best interest decisions ethically. It may also suggest a resistance to applying ethical principles, similar to the resistance that will be seen with the hardliner doctors.

2.4 Role of lawyers

Dr 10 was the only softliner who spoke about lawyers and again the context in which he did so was qualitatively different from the discussions about lawyers with the hardliner doctors discussed later in this chapter. Dr 10 sought out the company of lawyers. He spoke of an annual meeting in his region of senior paediatricians, judges, barristers and solicitors who specialise in paediatric medical law to discuss legal and ethical issues. He spoke positively about the meeting, and of how he believed it helped doctors and lawyers to better understand each other's points of view. Talking of the senior lawyers he did, however, say "*we thought they would be hot on the legal stuff, but they are not [laughs].*" While Dr 10's enthusiasm for the meeting seems to suggest a 'with

the law' legal consciousness, with the senior lawyers being accessible, at least to elite senior paediatric consultants, his comments do raise the question of whether in his jokey dismissal of senior lawyers' expertise in the law, Dr 10 was also exhibiting some resistance to the law.

2.5 Law resolving disagreements

The softliners, however, seemed far less resistant to law than the hardliners. For example, while still seeing the court as a place of last resort, the softliners also saw the court as place where disputes can be resolved. This was a construction of legality suggested by Dr 10 when he raised the case involving Neon Robert, *An NHS Trust v SR* [2012]¹⁰³³ as discussed at the start of this chapter. There was no sense in Dr 10's interview, in contrast to that of the hardliner doctors, that a best interest application to the court was not in any way either a threat to a doctor or undertaken with the view to providing the doctor with a shield. He spoke about the case as being about protecting the child's best interests, much more of a 'with the law' legal consciousness, or 'law as a shield', that would protect the child's best interests, rather than those of the doctor.

Dr 29, another softliner doctor, seemed to construct legality in a similar way. He discussed the David Glass litigation,¹⁰³⁴ discussed at length in chapter two¹⁰³⁵ but did so only after being asked about the influence, if any, of legal cases on his practice. This contrasted with the hardliners who cited legal cases without being prompted. Dr 29 questioned the behaviour of the doctors treating David Glass, in particular criticising them for giving David diamorphine and for not applying to court for a determination of David's best interests. Once again, it

¹⁰³³ *An NHS Trust v SR* [2012] EWHC 3842 (Fam)

¹⁰³⁴ *Glass, R (on the application of) v Portsmouth Hospitals NHS Trust* [1999] EWCA Civ 1914; *Glass, R (on the application of) v Portsmouth Hospitals NHS Trust* [1999] EWHC Admin 343

¹⁰³⁵ Chapter two, para 7, pp. 61-75

seems a softliner saw the law as a shield to protect the child, and expressed a 'with the law' legal consciousness, in contrast to the fear of and hostility to the law seen with the hardliner doctors.

2.6 Not mentioning the law

Until prompted, Drs 18 and 32 did not mention the law, the courts or any legal cases at all. Both discussed issues that could be framed as legal, but even when prompted, both chose instead to frame the issues they discussed as ethical. Both spoke in detail about what they clearly perceived to be PICU consultants' discriminatory behaviour towards disabled children, but neither used legal terms such as 'discrimination'. Dr 32 framed the PICU consultant's behaviour as being unethical. Dr 18 did not expressly label her fellow PICU consultant's behaviour, but did attributed it to them being misinformed, largely she believed because they lacked knowledge of disabled children's lives and experience outside their immediate working environment. When asked about the role of law, she said this is something "*that is more likely between the parents and the doctors*", again suggesting a perception of law as limited to litigation, in keeping with Ewick and Silbey's 'before the law' schema.¹⁰³⁶

To summarise: in contrast to the hardliners discussed below, the way softliner doctors approach best interest decisions suggests law is very much in the background. It is distant, but when needed it is helpful. It is a shield to protect the child, to ensure the child's best interests are met. Ethics are more prominent in softliner doctor's construction of best interests, with doctors who do not seem in the softliner's view to value disabled children and their families, being seen as behaving unethically.

¹⁰³⁶ Ewick, P, Silbey, SS, (1992) Conformity, Contestation and Resistance: An Account of Legal Consciousness, *New Eng. L. Rev.*, Vol. 26, & Ewick, P, Silbey, SS (1999) Common Knowledge and Ideological Critique, *Law and Society Rev.*, 33, 1027

There is far less resistance to law as, it is found in the books, from the softliners. Law is not generally seen as a threat, indeed, unless it is needed to resolve a disagreement as to a child's best interests, it is not seen as particularly relevant.

Best interest decisions are much more part of the stuff of everyday life for softliner doctors, about good communication and good relationships. For them, best interest decision-making seems to be about conversations and discussions with a broad range of actors. It does not seem to be primarily a clinical or a legal decision, but more a human interaction.

3. Hardliners

Four doctors classified as hardliners were interviewed. As was mentioned earlier, Dr 17 seems to be on the hard end of the hardliners. Dr 24 was at the soft end of the hardliners, Dr 14 and Dr 7 were between the two. The doctors have not been classified as hardliners or softliners according to how much they spoke about law, but analysis of the doctors' interviews does seem to suggest that the more hardline a doctor was, the more he or she talked about the law in their interview. As was just shown, the softliners tended to talk much more about relationships and communications. It was also seen in chapter six¹⁰³⁷ that the hardliners seemed to use heuristics to guide their decisions, whereas the softliners tended to make their decisions based much more on the circumstances of the individual child. This does raise the possibility that the hardliners talk so much about the law because they are more drawn to clear rules than the softliners. However, a detailed analysis of the hardliners' discussions shows considerable ambivalence towards the law. Each of the hardliner doctors will now be discussed in turn.

¹⁰³⁷ Chapter six, para 4.2, p.249

3.1 Dr 17

Dr 17 perhaps illustrates this ambivalence the best. She talked about the law a great deal in her interview. She spoke fast, with noticeable passion, in long bursts, at times hardly pausing for breath. She spoke about her education in law, as well as in ethics. She spoke about the eminence of her course tutor, and gave details of her studies. She spoke with pride of teaching junior doctors about the law and being viewed by colleagues as a legal expert. During the discussion Dr 17 was very keen to display her knowledge, seeming at times to revert to a teaching mode, explaining in great detail her understanding of legal and ethical concepts. Her discussion expressed a strong sense of pride in her legal and ethical knowledge. She was very confident and certain, although several of the statements of fact she made about legal cases or particular statutes were confused, for example confusing the ECHR¹⁰³⁸ and the HRA.¹⁰³⁹ She spoke about being able to influence junior doctors' and other's best interest decisions, using her legal knowledge. Dr 17 also said she believed training in law and ethics should be, just as life support training is, compulsory for all PICU consultants. As well as describing herself as a hardliner, she also described herself as an "outlier" both in her approach to best interest decisions for disabled children and for her interest in law and ethics. She said "*the average intensivist does not think about it [law and ethics] much*".

Her remarks suggested that law and ethics were central to Dr 17's conception of best interest decisions. She spoke of choosing to study law and ethics to provide her with a framework to make these decisions. She said

"I was making some really tough decisions and I was making them in a medical framework, but not in a legal or ethical framework. People [senior medical colleagues] told me what was right but they didn't give me the framework and I kinda of realised that there was a framework and I needed to learn more about it."

¹⁰³⁸ Council of Europe, *Convention for the Protection of Human Rights and Fundamental Freedoms* (European Convention of Human Rights0, as amended, 1950)

¹⁰³⁹ Human Rights Act 1998 c. 42

Dr 17 conveyed a sense of the power of law in her discussions. Her legal consciousness here seems to fit within Ewick and Silbey's 'with the law' schema,¹⁰⁴⁰ empowering and helping Dr 17 to achieve her aims. There is no sign of resistance here. There are perhaps also elements of Halliday et al's 'law as a sword' schema¹⁰⁴¹, but the way Dr 17 talks about the law here seems slightly different from that. There was a strong sense in Dr 17's remarks of the personal and professional power law gave her. She spoke of how her legal and ethical knowledge empowered her to reason with parents and colleagues, how it gave her a position of authority and power within her hospital Trust, suggesting her perceived expertise in the law, made her an ultra-elite within her Trust. She also spoke of the intellectual stimulation she gained from studying and debating about law.

Perhaps because their studies have been of marginalised groups, this is not a legal consciousness schema really found in Ewick and Silbey's or Halliday et al's schema and certainly not in Harding's three types of resistance schema.¹⁰⁴² Although Ewick and Silbey's 'with the law' and Halliday et al's law as a 'sword' are in part about the law empowering their study participants, that empowerment seems to be limited to the context of the problem they are facing. Ewick and Silbey's 'before the law' schema constructs law as powerful, but again differently from what seems to be the case here. 'Before the law' casts law as powerful, but distant and fear inspiring. With Dr 17's legal consciousness, there seems to be a sense of her embracing the law and being empowered by it both personally and professionally. She seems to gain 'kudos' from her perceived expertise, enhanced status and admiration from colleagues.

¹⁰⁴⁰ Ewick, P, Silbey, SS, (1992) Conformity, Contestation and Resistance: An Account of Legal Consciousness, *New Eng. L. Rev*, Vol. 26, & Ewick, P, Silbey, SS (1999) Common Knowledge and Ideological Critique, *Law and Society Rev*, 33, 1027

¹⁰⁴¹ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74

¹⁰⁴² Harding, R, (2010) *Regulating Sexuality: Legal Consciousness in lesbian and gay lives*, Routledge, Abingdon

She suggests in her discussion that law also gives her power over colleagues, junior doctors, patients and families. **'Law as kudos' is therefore suggested as an additional schema of legal consciousness, to supplement Halliday et al's schema of 'law as a sword'; 'law as a shield'; 'law as a barrier' and 'collective dissent'.**

It is anticipated that this schema will be found most often among elites, who have easier access to legal education and who are already in positions of respect and power. It seems possible to imagine that while studying law and ethics may provide individuals from marginalised groups with a sense of personal empowerment, outside of legal professions, it seems they will be less likely to be allowed to use their knowledge of the law to enhance their professional status in the way Dr 17 seems to suggest she has done. As was discussed right at the start of this thesis,¹⁰⁴³ Basnett¹⁰⁴⁴ explains how doctors can be perceived as experts in everything to do with disabled people's lives, even when there may be others, including in some circumstances the disabled person themselves, who have far more expertise about the topic under discussion. There is a sense from Dr 17 that she, and her colleagues, have attributed to her significant expertise in law after she completed a relatively short and limited course of study.¹⁰⁴⁵ This is also another example of the relational nature of legal consciousness. Dr 17 is empowered by law because her colleagues allow her to be so empowered and seem, from Dr 17's account, to provide no resistance to this empowerment. It is also relational as Dr 17 suggests she is an expert in law, in relation to her colleagues, though she would perhaps not be viewed as such by lawyers.

¹⁰⁴³ Chapter one, para 1, p. 1

¹⁰⁴⁴ Basnett, I, (2001) 'Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467, p.452

¹⁰⁴⁵ Dr 17 gave details of the course she studied, but details are not given in this thesis as to do so may make Dr 17 identifiable to colleagues.

Dr 17 is the only doctor interviewed who seemed to clearly express this legal consciousness, but other doctors interviewed, both hardliners and softliners, talked about medical colleagues, usually like Dr 17 also PICU consultants, who from the doctors' descriptions seem to possibly express this legal consciousness. Of course, those doctors would have to be interviewed to properly explore their legal consciousness, as it is how those individuals conceptualise the law that is important in legal consciousness studies. As was seen in the last chapter, the PICU consultants in this study did seem more likely to study law and ethics, which perhaps explains why, as a sub-specialism, they seem potentially more likely than other doctors to exhibit 'law as kudos' legal consciousness.

Dr 17's 'law as kudos' legal consciousness is, however, just part of the picture. Like other hardliners, Dr 17 expressed ambivalence towards the law. While half of her discussion was about the power she personally and professionally gains from law, the other half of her discussion, in stark contrast, conveyed a strong fear of law. Dr 17 talked of her fear of being struck off by the GMC and losing her livelihood if she acted in what *she* believed to be a child's best interests. She also talked of her fear of being challenged in court by a colleague or parent who took '*a different view from her*' as to the child's best interests. At first sight it is perhaps hard to reconcile Dr 17's law of kudos legal consciousness with the fear of and resistance to the law she seems to express. However, it seems possible that Dr 17 has developed the former to protect herself from the later.

Dr 17 spoke very passionately, even angrily about the case of *A NHS trust v MB [2006]*¹⁰⁴⁶ a case with which she said she was familiar as it involved a doctor she knew well. Dr 17 was highly critical of the judgment that MB, an infant with

¹⁰⁴⁶ *A NHS trust v MB* [2006], EWHC 507 (Fam)

spinal muscular atrophy type 1, (a severe degenerative condition, usually fatal within infancy), should continue to be ventilated. Dr 17 interpreted the case as placing upon her an unwelcome obligation to advise other parents of the possibility of ventilation for their child. She said:-

“[T]his has been driven as much by society as it has been by medicine, perhaps some of the time we have not been paternalistic, but there is self preservation there. If I’m paternalistic and someone challenges me, I’m going to end up struck off, I’ve got to earn a living and I’ve got to balance my feeling that I should do the right thing for the child versus can I go to court pick a fight here, loose my reputation”

From her comments, Dr 17 seems to view the law here as a threat, forcing doctors to act against their better judgment out of fear of losing their reputation and livelihood.

Dr 17’s strong fear and indeed anger was clear in the passionate way she discussed these concerns. While the anxiety that Dr 17 feels is clearly real, the extent to which this fear is well founded, however, does perhaps need further examination. Dr 17, as was seen, expressed anxiety at the prospect of losing her registration if she acted in what she believed to be the child’s best interests, if this contravened in her words, society’s expectations as to a child’s best interests. The GMC, the body whose statutory purpose is ‘to protect, promote and maintain the health and safety of the public by ensuring proper standards in the practice of medicine’,¹⁰⁴⁷ would be the body who would investigate and bring any action against Dr 17. Doctors risk sanction if they fail to comply with the GMC’s guidance ‘Good Medical Practice.’¹⁰⁴⁸ There is nothing in the GMC guidance to suggest that a doctor would be sanctioned for acting in what the

¹⁰⁴⁷ GMC, (2014), *Letter to Public Petition Committee of the Scottish Parliament*, gmc.u..org/GMC_reponse_to_the_consultation_on_the_Scottish_Parliament_Public_Petition_Committ ee_58721416.pdf accessed 30 September 2017

¹⁰⁴⁸ GMC (2013) ‘*Good Medical Practice*’, GMC, <http://www.gmc-uk.org/guidance/>, last accessed 30 September 2017

doctor believed to be a child's best interests, indeed, that is what doctors are guided to do.¹⁰⁴⁹

Moreover, if someone other than a doctors' employer complained there seems to be little likelihood that the GMC would investigate. The GMC's annual statistics¹⁰⁵⁰ report that 80% of complaints about doctors received from members of the public in 2015 were closed with no investigation being conducted. The statistics do not deal expressly with complaints about best interest decision making. However, such a complaint would seem to fall under the GMC 2015 heading of 'Clinical competence and communication and respect for patients allegations'¹⁰⁵¹Of these complaints the GMC report for 2015:

'92% of investigations involving clinical competence from members of the public resulted in no sanction or warning. Moreover, only a very small percentage of clinical competence investigations resulted in a sanction or a warning; 71% from other doctors and employers and 76% from all others resulted in no sanction or warning'¹⁰⁵²

The GMC's statistics suggest that the anxiety Dr 17 expressed about being sanctioned if she "*acted in a child's best interests*" against society's wishes is perhaps disproportionate to any real risk, even if someone were to complain. This, however, illustrates, how it is the individual or group's perceptions that are important in the construction of legal consciousness. Dr 17 perceives herself to be at risk of sanction from the GMC or a court if she acts in what she believes to be in the child's best interests and it is this fear, which helps construct both Dr 17's best interest decisions and her legal consciousness.

¹⁰⁴⁹ GMC, (2014), *Good Medical Practice, 0-18 Years Guidance*, GMC, para 8, last accessed 30 September 2017

¹⁰⁵⁰ GMC (2015) '*The state of medical education and practice in the UK: 2015*', GMC, Chapter 2, p.70, http://www.gmc-uk.org/Chapter_2_SOMEPEP_2015.pdf_63501223.pdf_last accessed 30 September 2017

¹⁰⁵¹ *Ibid*, p.66

¹⁰⁵² GMC, (2015) '*The state of medical education and practice in the UK: 2015*', GMC, Chapter 2, p.70 last accessed 30 September 2017

Dr 17 suggests that she sees her assessment of a child's best interests to be in conflict with a societal norm of the child's best interests. This is also revealing with regard to Dr 17's legal consciousness. Dr 17 also talked about the heuristics she used, such as allowing a child with cerebral palsy just one admission to PICU or not admitting a physically impaired child who is unable to perform a particular physical task, to PICU. She also spoke about, as seen, being both a 'hardliner' and an 'outlier'. There is a strong sense here of Dr 17 expressing the stabilising resistance Harding found in her study participants. Harding described stabilising resistance, as being always present when power relations exists.¹⁰⁵³ She describes how participants do not directly challenge the law or norms around them but live their lives in ways which challenge these norms.¹⁰⁵⁴

Dr 17 suggests her treatment of disabled child patients is out of step with that of her colleagues and she believes, society, but she challenges these norms by withholding and withdrawing treatment from disabled children in circumstances she suggests most (but not all) of her colleagues would provide treatment. Dr 17 resists what she perceives as pressure from society to treat disabled children in a way she does not believe to be in those children's best interests. However, while resisting what she sees as the norm, Dr 17 also expresses her strong sense of vulnerability before the law, talking as she does of her fear of being taking to court and losing her livelihood and reputation. In these parts of her interview, Dr 17 seems to convey much more of an 'against the law' legal consciousness within Ewick and Silbey's schema or 'law as a sword' within Halliday et al's; depicting law as distance, something to be feared and dangerous.

¹⁰⁵³ Harding R, (2010), *Regulating Sexuality: Legal Consciousness in lesbian and gay lives*, Routledge, Abingdon p 45

¹⁰⁵⁴ Ibid, p.46

This legal consciousness seems most intense for Dr 17 when she cited the case of *A NHS trust v MB [2006]*.¹⁰⁵⁵ Her anger, especially towards the judge Justice Holman, was palpable. She described the judge as being out of touch with the realities of clinical practice. This sense of judges, indeed, the law generally, as being out of touch with the realities of clinical practice was conveyed by other hardliner doctors (but not by softliners), as was a legal consciousness of resistance, as will now be discussed.

3.2 Dr 14

Dr 14, expressed a strong sense of the law being out of touch with the realities of best interest decision-making. Discussing the role of the court in best interest decisions, he said:

“I think judges ordering doctors to do something I would refuse, even if it were in contempt, because I don’t think it is right that judges should order doctors to do things, if they do not believe [they] are right. I think judges of course have a huge amount of insight and wisdom, but I don’t think they know what it is like at the coal face making medical decisions.”

The strength of Dr 14’s resistance to the law can be seen in his statement that he would sooner be held in contempt of court than comply with a court order with which he disagreed.

There are, again, strong echoes here of the resistance shown by Harding’s participants.¹⁰⁵⁶ However, assuming Dr 14 were to carry through with his claim that he would risk sanction for contempt of court, his resistance seems to be closer to Harding’s ‘fracturing resistance’ rather than the stabilising resistance, Dr 17 seems to express. Harding describes fracturing resistance, it will be recalled, as acts of resistance requiring an immediate response from the

¹⁰⁵⁵ *A NHS Trust v MB [2006]*, EWHC 507 (Fam)

¹⁰⁵⁶ Harding, R, (2010) *Regulating Sexuality: Legal Consciousness in lesbian and gay lives*, Routledge, Abingdon

government.¹⁰⁵⁷ It is assumed the judge would feel compelled to act if a doctor acted in deliberate contravention of a court order. Dr 14's resistance may not, however, be as forceful as it at first appears; earlier in his interview Dr 14 said he agreed with the well-established legal principle that a judge will not interfere with a doctor's clinical autonomy,¹⁰⁵⁸ so seems aware that it is unlikely that a judge would order him to do something contrary to his clinical judgment. Indeed, it does seem that it would only be a situation similar to the case of *Re MB*¹⁰⁵⁹ where Holman J, refused to grant an order allowing doctors to withdraw MB's existing life support, that the potential for a doctor to resist a court order with regard to a child's best interests would arise. A doctor refusing to comply with such an order would certainly be expressing fracturing resistance and potentially, it seems, be risking a charge of murder. Whether Dr 14's resistance went this far is unclear from his remarks. As was seen in chapter six¹⁰⁶⁰, he expressed the view that best interest decisions are in his words a matter of 'roulette', dependent much more on characteristics pertinent to the doctor than anything to do with the child. As will be recalled, he said that even twelve different respiratory consultants are likely to come to twelve different opinions about the same child. It does then seem perhaps surprising that he expressed such a strong view that a doctors' opinion should not be subject to challenge by the law, when he acknowledges that doctors' opinions vary widely and that they were based more on a doctor's values than a child's best interests. Like Dr 17, Dr 14's seems to express an 'against the law' legal consciousness within Ewick and Silbey's schema and to fit within Halliday et al's 'law as a sword' schema, constructing law as being alien, distance and threatening.

¹⁰⁵⁷ Harding R, (2010), *Regulating Sexuality: Legal Consciousness in lesbian and gay lives*, Routledge, Abingdon p. 48

¹⁰⁵⁸ *Re J (A Minor) (Wardship: Medical Treatment)* [1991] [1991] Fam. 33; [1991] 2 W.L.R. 140; per Lord Donaldson

¹⁰⁵⁹ *A NHS Trust v MB* [2006], EWHC 507 (Fam)

¹⁰⁶⁰ Chapter six, para 6, p. 256

Also like Dr 17, Dr 14 seems to embrace more than one legal consciousness when making best interest decisions, suggesting ambivalence towards the law. As has been seen, Dr 14 expressed resistance to law's power, constructing law as a threat to doctors, something to be avoided. However, contradictorily, Dr 14 also said that his own experience of the courts had been positive. He explained how dealing with a medical case it is very easy for all the parties including the doctors to become "*blinkered*" but a case being considered by the court could be helpful in resolving this. He described his own experience in court saying the doctors and the child's parents had found the whole process very helpful. He said it was an opportunity for all the evidence to be explored in full by "*protagonists not directly involved*" and to hear evidence from people at the cutting edge in the field. He also said it enabled him to understand things from the parents' perspective, and that he thought the parents had found the process helpful for similar reasons.

This conveys a different legal consciousness on Dr 14's part, more in keeping with Ewick and Silbey's 'with the law', enabling the doctors to achieve their aims, or Halliday's et al's 'law as a shield' schema, and like the relatives in Halliday et al's study, Dr 14 here shows respect for law's role as an impartial and powerful force. The power of law here is still seen, but in contrast to elsewhere in Dr 14's discussions, it is an impartial not hostile power.

In chapter seven, the way in which an individual or group's experiences all contribute towards the construction of a legal consciousness was discussed,¹⁰¹⁵ and this is apparent here. Dr 17 and Dr 14's relational legal consciousness can be seen to be constructed in part by their personal experiences. Dr 17 resisted law and constructed it as alien, and hostile threat based, as described with respect to her colleagues' experience in *A NHS trust v MB [2006]*,¹⁰⁶¹ where the judge had ruled in keeping with the family's and not the doctors' view of the child's best interests. Dr 17's personal connection with the case, knowing one

¹⁰⁶¹ *A NHS Trust v MB [2006]*, EWHC 507 (Fam)

of the doctors involved, seems to have increased the impact of the case on the development of her legal consciousness. Dr 14's legal consciousness likewise constructs law as hostile and threatening when he imagines a judge ruling against him. However, when a judge agreed with his view as to a child's best wishes, as the judge did in an actual case, Dr 14 constructs the law as a positive force. This is important, because if doctors conceive of law negatively then it seems likely they will avoid the law. However, if doctors conceive of law as being potentially positive, it seems more likely that doctors will apply to court for a disabled child's best interests to be determined, when there is disagreement as to what is in an individual child's best interests, potential protecting that child's legal rights.

Dr 14 was also one of two hardliners who mentioned the criminal trial of Dr Arthur¹⁰⁶² for the manslaughter of a baby with Downs syndrome, discussed in chapter two.¹⁰⁶³ Dr 14 had not studied any law or ethics. He would have been at the start of his medical career at the time of the trial, (so at the older age range of doctors in this study) which may explain why the case made such an impression.

Dr 14 also talked about referring cases to his hospital's clinical ethics committee but said he had not found the experience helpful. He complained that the clinical ethics committee dealt with abstract philosophical ethics but did not address the everyday ethics of the problems before them. There were echoes in what he said about the clinical ethics committee with the resistance he and other hardliners had shown to judges and the courts. Both are criticised by hardliners for being out of touch with the realities of clinical practice. This

¹⁰⁶² *R v Arthur* [1981] 12 BMLR 1, heard before Farquharson J, 3-5th November, 1981

¹⁰⁶³ Chapter two, para 2, pp. 36-43

echoes the disappointment in the power of ethics expressed earlier by softliner Dr 1¹⁰⁶⁴ Dr 14 went on to say:

“so in a sense it almost seems to me, that as it stands right now, that we go through a process just to say we have been through the process when the case comes further down the line. If one was in court for instance and we had a clinical ethics committee and had not been to it, you know, it would look pretty odd.”

Dr 14 suggests he refers cases to primarily to avoid criticism from the court, rather than to ascertain a child’s best interests, suggesting again that the law and the courts are seen as a threat to doctors, in keeping with Ewick and Silbey’s ‘Before the Law’ schema.

3.3 Dr 7

Dr 7 like Dr 14 also mentioned the trial of Dr Arthur. Like Dr 14, Dr 7 had not studied any law or ethics and also like Dr 7 he had been at the start of his medical career at the time of the trial. Dr 7, however, mentioned the case in the context of expressing his relief that doctors no longer behave in the way Dr Arthur did. Dr 7 said he believed the case was:

“the start of a number of actions taken and then that led to the sort of situation, where if you wanted to withdraw care and the family did not agree you could go to law and the judge could rule that it was not unlawful to withdraw care.”

This suggested a construction of legal consciousness as ‘law as a shield’, within Halliday et al’s schema. Dr 7 however, was describing, in his view, other doctors. He rejected this construction of the law for himself, saying:

“but I have never been involved in that level of thinking. The law is too clumsy to deal with complex human emotion here. You have to take people with you and settle it that way I think. Or they take you with them indeed”

There are echoes here of Dr 17’s and Dr 14’s resistance to the law and in particular to judges, as lacking the ability to understand the complexities of day-

¹⁰⁶⁴ Chapter nine, para. 2.3 p.358

to-day clinical practice and decision-making. But Dr 7 is further to the soft end of the hardliners than those two doctors and expresses himself differently, talking about the law being “*too clumsy to deal with the complexity of human emotions.*” This comes across perhaps as less defensive than Drs 17 and 14 and, as was seen, closer to the softliners construction of best interest decisions as being concerned with relationships and good communication.

Dr 7 did convey a sense that applying to court was an admission of failure on the part of a doctor, like other hardliners resisting the law and constructing it as a place of last resort, in keeping with Ewick and Silbey’s ‘before the law’ schema and Halliday et al’s ‘law as a sword schema’. Dr 7 seems to resist the law as he seems to construct this as a failure to maintain good relationships, putting him very close to the softliner construction of best interests. But Dr 7 depicts the law as a place best avoided, not part of a framework within which he works and lives.

3.4 Dr 24

Resistance to the law was also seen from Dr 24, the final hardliner, albeit also at the soft end of the hardliner spectrum. Speaking of the relevance of law to her best interest decisions, Dr 24 said:

“It is kind of the last port of call when you are desperate really, when you are genuinely very, very stuck the law, the court is the place where it is legally decided and for us as professionals. It is a bit defensive but if you have taken it to the court and the court has decided it takes the responsibility off you. You know, nobody is going to come along and charge you with manslaughter or murder the next day, because of the decision you took, because the court is the final point, so for some of us it is a kind of protection and it is good to know if we are really struggling it can be there I think, but I think it would generally be so much better if we did not have to go there”

Like the other hardliners Dr 24’s legal consciousness constructs law as a distant place, somewhere that doctors have to go to, not part of her everyday life but as she describes it, “*a place of last resort,*” in keeping with Ewick and Silbey’s ‘before the law’ schema. But law is seen here by Dr 24 as a place doctors turn

to defensively for protection, in keeping with Halliday et al's, depiction of law as a shield, protecting the doctors from law's harsher sanctions – a murder or manslaughter charge. Although Dr 24 said it would be better not to go to court, rather than resisting the law like the other hardliners, she seems to see it as providing doctors with protection.

It is noteworthy that Dr 24 talks of applying to court to provide protection for doctors, rather than a best interests application being to protect the child by determining his or her best interests. This echoes what Dr 14 said earlier when talking about clinical ethics committees.¹⁰⁶⁵

Although Dr 24 did not seem to express resistance when talking about applications to court, she did exhibit resistance to the disability and child rights legislation introduced during the years of her practice and discussed in chapter two.¹⁰⁶⁶ Just as the other hardliners suggested judges and the courts could not deal with the complexity of best interests decisions for disabled children, Dr 14 said the same about this legislation, especially disability anti-discrimination legislation and training for doctors.¹⁰⁶⁷ As was seen in chapter six,¹⁰⁶⁸ Dr 24 criticised junior consultants who she believed were overly influenced by this legislation, saying that training made them, in her view, too willing to treat disabled children. Dr 24 said younger consultants put too much weight on their disability awareness training, to the detriment of best interests.

Many contradictions can be seen in the way the hardliners construct legality and this is perhaps another of them. Dr 24 is both highly critical of PICU consultants

¹⁰⁶⁵ Ibid

¹⁰⁶⁶ Chapter two, pp. 23-94

¹⁰⁶⁷ Chapter six, para 7.1.3, pp.267-268

¹⁰⁶⁸ Ibid

for discriminating against disabled children and critical of junior consultants for being influenced by anti-discrimination training and legislation. This is an example of roster uncertainty discussed in chapter six.¹⁰⁶⁹ It seems both a doctors' awareness of legislation and the doctors' values in relation to that legislation play a part in how doctors construct their best interest decisions and their legal consciousness. There is certainly a sense with Dr 24 and other doctors in this study such as Dr 14, that they seem to construct legality in such a way that law, as it appears in the books, is something they will follow if they agree with it, but resist if they do not agree with it. This is perhaps another way in which a doctors' elite status plays a part in a doctors' construction of legality, with a doctor's elite status giving him or her more power to choose whether to follow law than ordinary citizens, because of the authority given to doctors to decide for disabled patients as Basnett identified.¹⁰⁷⁰ This is something that is addressed more in the final concluding chapter of this thesis where the courts' deference to doctors is considered for further research.

To summarise: what can be concluded about hardliners' use of law in their best interest decisions. The hardliners seem to show ambivalence towards the law. At times, as was seen particularly with Dr 17, but also with the other hardliners, they embrace the law, looking to it to provide them with protection. Sometimes, perhaps emphasising the ambivalent nature of hardliners' relationship with the law, that sought after protection, is often from the law itself. Dr 17 and from participants accounts, other doctors, especially PICU consultants, seems to show an embodiment of legal consciousness not reported by legal consciousness scholars. This may be because this is an embodiment of legal consciousness that requires elite status. This is a legal conscious of law

¹⁰⁶⁹ Chapter six, para 6, pp.256-261

¹⁰⁷⁰ Basnett, I, (2001)' Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467, p.452

providing personal and professional empowerment. As was seen, this legal consciousness has been labelled 'law as kudos'.

At other times, hardliners resist the law, there is a strong sense of fear of the law in their discussions. The hardliner doctors' feelings of vulnerability came across very strongly in their discussions, illustrating, as was discussed in chapter four,¹⁰²⁵ that elites do not necessarily perceive themselves to be elite and it is their own perceptions of themselves which constructs their legal consciousness. As was seen with Dr 17 it is possible that on occasions this fear is misplaced due to an incomplete understanding of the law.

The law seems to overshadow hardliners' best interest decisions. Law as it is in the books seems to be at the forefront of hardliner doctors' minds when they make best interest decisions for disabled children.

While law is ever present, it seems, however, that it does not provide the doctors with a structure and guidance as how to make their decisions, but rather it seems to stimulate fear and resistance. It was noticeable, as was discussed, that hardliner doctors tended to talk about the law in relation to themselves and the impact on themselves rather than in relation to the children they are treating. This echoes what doctors said about using guidance in their survey responses, where, doctors reported either not using guidance at all, or using it to justify their decisions, rather than to guide them. Dr 14 who had direct personal experience of a best interest applications to court, did however, report the experience to be a positive one, despite his own strongly expressed fear of, and resistance to, the law.

The lack of reference to ethics by hardliners was noticeable. As was seen both Dr 14 and Dr 17 did talk about ethics in the context of referring cases to ethics committees or in Dr 17's case sitting on ethics committees. As with law, ethics seems to be conceived as a process: the process of taking a case to an ethics committee, rather than a framework for practice or intellectual exercise.

This chapter now turn briefly to rights and their absence from doctors' discussions.

5. Rights

Before concluding this chapter, mention must be made of rights, because thirty doctors (91%) said in their survey response that they actively considered a child's rights when making a difficult decision for disabled children. However, rights were only raised three times by doctors in their interviews, always by hardliner doctors. Dr 17 said she taught junior doctors about the Human Rights Act and that the right to life is not absolute. If as she seemed to suggest, her teaching of rights is limited to this one concept, it does seem that possibly Dr 17 is again using 'law as a shield' selectively teaching the junior doctors just about rights from a doctor's protection perspective, not from the child's.

Dr 14 criticised the courts for taking what he described as a "*right to life*" approach to best interest decisions. Dr 24 did say, when asked about the relevance of rights to her best interest decisions "*we have to be mindful of a child's rights, nobody should be wanting to override the rights of the child*" But as was noted earlier, Dr 24 was highly critical of her junior consultant colleagues for, in her view, putting too much weight on disabled children's equality rights.

Although 91% of the doctors said in response to the survey question that the child's rights are a factor doctors they consciously consider when making difficult decisions in for disabled children, there was nothing in the doctors interview discussions, or as was seen in the last chapter in their survey responses, to support this. It is possible that the doctors were aware when they answered the question that they would be expected to put weight on the child's rights, but it is not at the forefront of their mind when making best interest decisions.

6. Conclusions

To conclude, hardliner and softliner doctors seem to construct best interest decisions differently. The hardliner doctors seem to take a much more legalistic approach, where the law seems ever present, but at the same time they are much more ambivalent about the law, embracing it when it provides them with a shield, but being resistant to and fearful of the law at other times. There are signs of both stabilising resistance and fracturing resistance as described by Harding.¹⁰⁷¹ The doctors' elite status seems potentially to empower the doctors to resist the law in circumstances when ordinary people would not be able to do so. As such, Dr 17 comments appear to suggest a new schema of legal consciousness to compliment Halliday et al's four schema, that is, a schema of 'law as kudos', which it is also anticipated is usually only found among elites.

In contrast, for the softliner doctors best interest decisions are about human interactions, discussions, good communication and relationships. Best interest decisions are constructed as being part of everyday life. There are also elements of 'law as a shield', but when there is recourse to law as it is on the books, this is for the benefit of the child not the doctors. Law is then seen as a solution, and not a threat.

There does seem to be a suggestion of collective dissent from doctors to any law with which they do not agree, but as was seen, the doctors seem to vary in their reasons for resisting the law. Again, it seems likely that their elite status empowers them in this collective dissent.

It was said in chapter four¹⁰⁷² that for the purpose of this study the best interest test is constructed as a legal test, rather than a medical one. It might then be

¹⁰⁷¹ Harding R, (2010), *Regulating Sexuality: Legal Consciousness in lesbian and gay lives*, Routledge, Abingdon p. 48

¹⁰⁷²Chapter seven, para 2, p.290

expected that the hardliners who seem to take a much more legalistic approach than the softliners, would be found to be making best interest decisions much more in keeping with the norms established by the doctors' professional guidance and case law. However, an examination of the what the doctors said or do not say about law, rights and ethics, through the lens of legal consciousness scholarship finds that it is the softliner doctors' approach of wide ranging discussion and maintaining good relationships with all parties, that is much more in keeping with those norms as presented in doctors' professional guidance and case law, than the more legalistic approach of the hardliners.

There is no indication that studying law and ethics either hinders or assists best interest decisions making, although there is a strong suggestion that fear of the law hinders good best interest decision making. The next and final chapter of this thesis will draw together what has been learnt in the whole of this thesis about how doctors make best interest decisions for disabled children and what part if any the law, rights and ethics play in those decisions. It will consider the limitations of this thesis and consider what recommendations can be made from this study's findings.

Chapter Ten

Summary, Conclusions and Recommendations

1. Introduction

This final chapter begins by summarising the findings in respect of each of the four research questions, namely:

- (i) Which decisions do UK paediatricians find particularly difficult when working with disabled children and what makes those decisions particularly difficult?
- (ii) What factors do UK paediatricians take into consideration when making difficult decisions for disabled children, and what weight do they put on those factors?
- (iii) What formal education in law, rights and ethics have the doctors received and to what extent, if any, can we discern how this education impacts on their difficult decisions for disabled children?
- (iv) How do UK paediatricians construct and understand the law, rights and ethics, when making their difficult decisions?

This chapter then briefly draws overall conclusions, including considering this study's limitations. The chapter and the thesis conclude with recommendations for further research and potential changes in the law and practice, in relation to best interest decision-making for the UK's severely disabled children.

2. Summary of research question findings

2.1 Research question one

Almost all doctors in this study (94%) identified decisions whether to withhold or withdraw treatment in potentially life and death situations, as the most difficult ones they faced when working with severely disabled children with complex

health problems.¹⁰⁷³ (The two other doctors identified situations specific to their sub-specialisms).¹⁰⁷⁴ This finding is what I anticipated, based both on pilot discussions with three consultant paediatricians¹⁰⁷⁵ and my prior personal and professional experience in the field.¹⁰⁷⁶ However, the survey, as seen in chapter three,¹⁰⁷⁷ was worded in such a way that doctors were asked about ‘difficult decisions’. This was to allow for doctors to suggest decisions other than end-of-life best interest decisions, as the difficult ones they face when treating disabled children with serious health problems¹⁰⁷⁸

The doctors reported that communication with parents and uncertainty made these decisions particularly difficult.¹⁰⁷⁹ The doctors also identified disagreements between doctors as a major challenge for them when involved in end-of-life decisions for disabled children.¹⁰⁸⁰ Indeed, while 58% of doctors reported experiencing disagreements with parents as to a child’s best interests, 78% of doctors reported experiencing disagreements with medical colleagues. Disagreements with doctors was also the main topic the nine interviewed doctors chose to discuss.¹⁰⁸¹ That paediatricians *routinely* disagree strongly as to a disabled child’s best interests is perhaps a new finding, at least outside of

¹⁰⁷³ Chapter four, para 5.1, p.168

¹⁰⁷⁴ Ibid

¹⁰⁷⁵ Chapter three, para 4, pp. 108-109

¹⁰⁷⁶ Chapter one, paras 5.2 -5.3, pp. 12-21

¹⁰⁷⁷ Chapter three, para 3, p.106

¹⁰⁷⁸ If the majority or a significant minority of doctors had reported a different type of difficult decision, the focus of this thesis would have shifted to examine those decisions.

¹⁰⁷⁹ Chapter four, para 5.4, pp. 171-172

¹⁰⁸⁰ Chapter six, para 7, pp. 261-275

¹⁰⁸¹ Ibid

the paediatric community. This might be masked by high profile disagreements between parents and doctors that get into the public domain and media spotlight, when cases concerning children such as David Glass,¹⁰⁸² discussed in this thesis¹⁰⁸³ or the more recent cases of Ashya King¹⁰⁸⁴ and Charlie Gard¹⁰⁸⁵ illustrate. Doctors are however, understandably reluctant to refer colleagues to court when they disagree with their assessment of a child's best interests, keeping disagreements between doctors behind the closed walls of the hospital and out of the public domain. Indeed, doctors in this study suggested that, at times, doctors are even reluctant to voice their concerns or offer an alternative interpretation of a child's best interests to colleagues. This is even in circumstances where failure to do so will, in the doctor's view, result in the inappropriate withholding or withdrawal of treatment and the inevitable death of the child.¹⁰⁸⁶ As was seen, the doctors describe a culture of not wanting to 'rock the boat'.¹⁰⁸⁷

Three classes of uncertainty were identified and classified in this study, namely: (i) prognostic and diagnostic uncertainty¹⁰⁸⁸ (an uncertainty as to a child's condition or future); (ii) moral uncertainty¹⁰⁸⁹ (anxiety felt by doctors arising from the decision-making process and their part in it); and (iii) roster uncertainty (an

¹⁰⁸² *Glass, R (On the application of) v Portsmouth Hospitals NHS Trust* [1999] EWCA Civ 1914; *Glass, R (On the application of) v Portsmouth Hospitals NHS Trust* [1999] EWHC Admin 343; *Glass v UK* [2003] ECHR Admissibility Decision no. 61827/00

¹⁰⁸³ Chapter two, para 7, pp. 61-75

¹⁰⁸⁴ *Re Ashya King* [2014] EWHC 2964

¹⁰⁸⁵ *Great Ormond Street Hospital v Yates* [2017] EWCA Civ 410

¹⁰⁸⁶ Chapter six, para 7.1.1. pp.262-264

¹⁰⁸⁷ *Ibid*

¹⁰⁸⁸ Chapter six, para 4, pp. 244-251

¹⁰⁸⁹ Chapter six, para 5, pp. 251-256

uncertainty in the outcome for a patient, depending on the values of the doctor).¹⁰⁹⁰ While examined as three separate categories of uncertainty, the findings of this study suggest that the three are closely linked. Doctors' views as to a child's prognosis/diagnosis, particularly when these are value laden, seem to contribute both to the moral uncertainty the doctors describe and to the roster uncertainty identified.

2.2 Research question two

This study found a lack of consensus between the doctors as to the factors that should be included when making, what was framed in the study survey as difficult decisions for disabled children, (but quickly identified by the doctors as best interest decisions), and the weight to be put on those factors.¹⁰⁹¹ It also found a lack of consensus as to the people to be included in the decision-making process, ranging from doctors unilaterally taking decisions without consultation, to doctors consulting widely including with a multi-disciplinary team of professionals and non-health professionals, the child's parents and where possible the child. This included doctors who saw the child's parents as the ultimate decision-maker.¹⁰⁹²

The doctors drew on a wide-range of factors in their best interest decisions including clinical factors, such as the trajectory of the child's illness and the child's pain, and non-clinical factors, such as whether the child was happy or attended school.¹⁰⁹³ A doctor's personal and professional characteristics, including their sub-specialism, duration of practice, any personal experience of disability and religious faith all seemed to potentially impact on the weight a doctor put on the key factors of prognosis, futility, quality of life and a child's

¹⁰⁹⁰ Chapter six, para 6, pp. 256-261

¹⁰⁹¹ Chapter five, pp.181-236

¹⁰⁹² Chapter six, para 7.3.2, p. 277

¹⁰⁹³ Chapter four, figure 25, p.178

cognitive ability. However, the way in which personal and professional characteristics potentially impacted was variable, with some characteristics seeming to affect the weight doctors put on some factors but not others.¹⁰⁹⁴ Some patterns seemed to emerge, but there were exceptions to these. For example, there seemed to be similarities between the weight put on certain factors by neurologists (doctors with the most professional experience of disabled children) and by doctors who were parents of a disabled child (the doctors with the most personal experience of disabled children). In contrast, similarities were not seen between PICU consultants and parent doctors.¹⁰⁹⁵ This may help explain the finding that PICU consultants were more likely to report disagreements with parents (generally) than neurologists.¹⁰⁹⁶ It seems that there is possibly more agreement between neurologists and parents, than between PICU consultants and parents, as to the factors considered when making best interest decisions for a disabled child and the weight to put on those factors.

The findings from this research also suggest that doctors who qualified in the 1990s seemed to approach best interest decisions in several respects differently from doctors who qualified earlier. The data suggest that the 'hidden curriculum'¹⁰⁹⁷ is perhaps not as influential on younger consultants' best interest decisions for disabled children, as the literature on this phenomenon might otherwise suggest.

Although the doctors in this study seemed to take a very individualistic approach when making their decisions, two camps of doctors were identified:

¹⁰⁹⁴ Chapter five, pp.181-236

¹⁰⁹⁵ Ibid

¹⁰⁹⁶ Chapter six, para 7.3.1, p.276

¹⁰⁹⁷ Chapter three, para 2.2, pp.100-101

the hardliners and the softliners.¹⁰⁹⁸ The hardliners took a very 'rules' based approach to their decisions, for example, a rule that a cognitively impaired child should not have intensive care. They drew on heuristics and seemed to apply blanket rules, applying these with little or no wider consultation.¹⁰⁹⁹ They tended to stress the burdens of any treatments and the negative aspects of a disabled child's life. Hardliners tended not to have prior knowledge of a patient and to be called in to care for the child in a medical crisis.¹¹⁰⁰ In contrast, the softliners saw the decision-making process much more as a series of discussions that were dependent upon good communication between a wide circle of medical and non-medical parties. They tended to have longer-term relationships with the child, to stress the positive benefits of treatment and of a disabled child's life, such as the child's enjoyment of school or loving relationship with other family members.¹¹⁰¹

The different approaches of hardliners and softliners was seen to have the potential for optimum best interest decision-making, in keeping with doctor's professional guidance. Potentially doctors from either camp could contribute to the best interest decision, highlighting the benefits and burdens of treatment, to draw up a 'best interests balance sheet' in keeping with the jurisprudence of the English High Court.¹¹⁰² However, doctors suggested that, at least for the hardliners, this balancing exercise does not always happen, not least because of the reluctance of doctors to challenge colleagues if they did not agree with their assessment of a child's best interests.¹¹⁰³ This suggested that the two

¹⁰⁹⁸ Chapter six, para 7.2, pp. 268-273

¹⁰⁹⁹ Chapter six, para 4.2, p.249

¹¹⁰⁰ Chapter six, para 7.2, pp. 268-273

¹¹⁰¹ Ibid

¹¹⁰² See for example *An NHS Trust v MB* [2006], EWHC 507 (Fam), where Holman J made the 'best interest balance sheet' in that case available in his judgment.

¹¹⁰³ Chapter six, para 7, pp. 261-275

sides of the best interests balance sheet do not necessarily get considered, even when relevant information is available.

This finding is particularly relevant to this thesis in the light of its focus on disabled children, moving away from the usual focus on infants in the literature and 'case law'.¹¹⁰⁴ Key to this thesis is the argument that there is an important difference when making best interest decisions for children, when compared to infants, in the amount of information available to doctors about the child. It was argued that whereas for infants, doctors are forced by circumstances to make assumptions based on their and colleagues experience of other infants as to, for example, a particular infant's quality of life or cognitive ability, this can be avoided for older children. This information will be known and documented by a range of parties.¹¹⁰⁵ This study found, however, that the hardliner doctors seemed to continue to make assumptions about a disabled child, as they do for infants, rather than drawing on available known information about a child from a variety of sources, including medical colleagues. Moreover, the research found that doctors who do have this information are often reluctant to share it with other doctors, for fear of 'rocking the boat'. The net result is that there is evidence of a possible tendency not to undertake a wide-ranging exploration of a child's best interests.¹¹⁰⁶

2.3 Research question three

The doctors in this study, as was seen in chapter four,¹¹⁰⁷ included thirty-three paediatricians, all but one of whom were senior paediatric consultants working around the UK. Ten of the doctors were PICU consultants, nine were neurologists, and the remaining doctors were from a range of paediatric sub-

¹¹⁰⁴ Chapter One, para 2.2, p. 3

¹¹⁰⁵ Chapter five, para 5.3, pp.210-213

¹¹⁰⁶ Chapter six, para 7, pp. 261-275

¹¹⁰⁷ Chapter four, para 4, pp. 145-147

specialties. The doctors ranged from one doctor who qualified in the 1960s to a doctor (the specialist registrar) who qualified in 1998. The majority of doctors (20/33) qualified in the 1980s.¹¹⁰⁸ This study found that five 1990 qualifiers (71%) received significant ¹¹⁰⁹legal and ethical education and that none of this cohort reported having had no legal or ethical education. However, only two 1980s (10%) and one 1970s (20%) qualifiers were found to have had significant legal or ethical education.¹¹¹⁰ Two 1970s (40%) and fourteen 1980s qualifiers (70%) were found to have had no legal or ethical education at all.¹¹¹¹

However, perhaps most significantly, especially in the context of the Kennedy debate¹¹¹² and particularly the question he posed as to whether doctors are making ethical and legal decisions without the training and education to do so, this study found that almost half the doctors (48%) the majority of whom are routinely involved in the treatment of severely disabled children, including making end-of-life best interests decisions - have had no formal training or education at all in law, and ethics.¹¹¹³

This thesis also tested the claim made by the UK government to the UNCRC Committee¹¹¹⁴ that all professionals working with children in the UK receive training in children's rights. The finding that 48% of doctors in this study receiving no education or training at all in rights suggests that the government's

¹¹⁰⁸ Chapter four, para 4.5, pp. 157-158

¹¹⁰⁹ Chapter eight, para 2, pp. 328-332

¹¹¹⁰ Chapter eight, para 2, p.331

¹¹¹¹ Ibid

¹¹¹² Chapter two, para 2, pp. 25-34

¹¹¹³ Chapter eight, para 2, pp. 328-332

¹¹¹⁴ Chapter eight, para 2, pp. 331-332

claim is at best, an exaggeration. The seniority of the doctors is significant here: first, because they are the very doctors taking decisions which have life or death implications for disabled children; and secondly, the doctors have all been employed within the NHS for many years, most for several decades, so the opportunity to receive training should have presumably presented itself if, as the UK government suggest, such training is the 'norm' for all professionals working with children.

The thesis also mapped the doctors' legal and ethical education and training to their decision-making to see if there was any suggestion that doctors who had significant education and training approached best interest decisions differently from those who did not. The research findings reveal the picture to be unclear. The data from the doctors' surveys suggested that doctors who had received significant legal/ethical education potentially approached some aspects of best interest decisions differently from doctors with less or no legal/ethical education. For example, doctors with significant legal/ethical education were found to put more weight on prognosis as a factor in their decisions than other doctors; they were also found to be more inclined to put weight on both futility and a child's cognitive ability. They were, however, less inclined to put weight on a child's quality of life.¹¹¹⁵

Although these differences were found, it was unclear from the data whether the doctors who had more legal/ethical education approached these factors differently from their colleagues *because* of their legal/ethical education or for other, unrelated, reasons.

Moreover, the differences in approach by doctors with different levels of legal education found in relation to individual factors within a best interest decision, namely prognosis, futility, quality of life and cognitive ability, were not found

¹¹¹⁵ Chapter eight, para 3.3, pp. 337-338

when doctors discussed their best interest decisions as a whole, at interview. This study found no difference in legal/ethical education between the softliner and the hardliner doctors who seem to approach best interest decisions very differently. Indeed, similar numbers of doctors with significant, minimal and no legal/ethical education were found within the softliner and hardliner camps.¹¹¹⁶ In other words, a difference in approach was more likely to be found between softliner and hardliner doctors than according to level of legal and ethical education undertaken.

2.4 Research question four

It is in answering this final research question that legal consciousness theory comes to the fore. Drawing firm conclusions about a doctors' legal consciousness from the survey data is difficult due to the lack of depth and detail in the doctors' survey responses. However, there are suggestions in those responses, from fourteen of the doctors (42%),¹¹¹⁷ that they depicted law as a distant place, that it becomes relevant when things go wrong, and often to punish 'wrong' decisions. The survey responses suggest that for these doctors, law is about litigation, sometimes just criminal litigation, and not part of the fabric or framework of doctors' everyday lives and decisions. They seem, from the limited available data, to understand law in very narrow terms: that is, 'law as sword' within Halliday et al's legal consciousness schema.¹¹¹⁸ Although doctors' professional guidance¹¹¹⁹ tells them to ensure all decisions for children are made in a child's 'best interests', twenty of the doctors (60.5%) made no direct and clear references to 'best interests' or any statements that

¹¹¹⁶ Chapter nine, figure 62, p. 349

¹¹¹⁷ Chapter eight, para 4, p. 341

¹¹¹⁸ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74;

Halliday, S, Morgan, B (2013) I Fought the Law and the law Won? Legal Consciousness and the Critical Imagination, *Current Legal Problems*, vol. 66, pp.1-32

¹¹¹⁹ Chapter four, figure 11, p.144

could at first sight, be read as a proxy for best interests, in their survey responses.¹¹²⁰ Four doctors (12%) used the term ‘best interests’ or an obvious proxy and a further nine doctors (27%) cited factors, which are important elements of the best interest test.¹¹²¹ For example, balancing of benefits and burdens of treatment or consulting widely. It is noteworthy that all these references were made in the first half of the survey and none in response to questions concerning law and ethics. This suggests the doctors, who use the term best interests, see it as something other than a legal test, presumably as a medical one.

The research did, however, find that the doctors are possibly using other factors, particularly quality of life, as a proxy for ‘best interests’. The doctors defined quality of life to include a wide range of clinical and non-clinical factors, including wide welfare factors, such as the child’s happiness, schooling and family life.¹¹²² This is in keeping with the jurisprudence of the English High Court, which makes clear that a child’s best interests should be considered widely to include these wider welfare factors.¹¹²³

The semi-structured interview discussions allowed for much greater analysis of the legal consciousness of the nine doctors interviewed for this study. The research found that the doctors conceptualise best interests in two broad ways. Two ‘camps’ of doctors were identified, the hardliners and the softliners. These two camps are important in furthering an understanding of both how best interest decisions are made day-to-day in the real world and how different doctors conceptualise best interest decisions.

¹¹²⁰ Chapter four, para 6.4, pp. 178-179

¹¹²¹ As the test is set out in cases such as *Re J (A Minor) (Wardship: Medical Treatment)* [1991]; 2 WLR 140

¹¹²² Chapter five, figure 41, p.213

¹¹²³ Chapter two, pp. 23-94

The hardliners seem to take an almost deontological approach, that is, to conceptualise best interest decision-making as being about following a series of heuristics or rules, albeit ones the doctors have created for themselves. For example, the rule seemingly shared generally amongst the hardliners, that cognitively impaired children should not have intensive care treatment.¹¹²⁴ The softliners, in contrast, seemed to conceptualise best interest decisions as being about relationships between the various parties and good communication. They did not see law as being particularly relevant to their day-to-day decisions. This study did not, however, find the law completely absent from the softliners' understanding of best interest decision-making. As was seen,¹¹²⁵ law was seen to have a place within the softliners' conceptualisation of law, in protecting a child, acting as a 'shield' within Halliday et al's legal consciousness schema,¹¹²⁶

An important part of the claim to originality in this thesis relates to the fact that the research found not only the two camps of doctors in the hardliners and the softliners, but also a schema of legal consciousness which has not been previously described by legal consciousness scholars. This schema was most obviously seen in hardliners' conceptualisation of the law.

Doctors who embrace this legal consciousness, seem to gain power and status, especially among colleagues for their apparent legal expertise. This new legal consciousness draws on this sense of enhanced status and builds on the

¹¹²⁴ Chapter six, paras 7.1.1-7.1.2, pp. 262-266

¹¹²⁵ Chapter nine, para 4, pp. 347-380

¹¹²⁶ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74; Halliday, S, Morgan, B (2013) I Fought the Law and the law Won? Legal Consciousness and the Critical Imagination, *Current Legal Problems*, vol. 66, pp.1-32

schema identified by Ewick and Silbey,¹¹²⁷ Harding¹¹²⁸ and Halliday et al.¹¹²⁹ I have labelled this as 'law as kudos', in light of the kudos holders of this schema seem to feel. It is argued that it is at least in part the doctor's elite status that enables them to gain status or kudos from the law in this way.¹¹³⁰ This schema emphasizes the relational nature of legal consciousness, as how colleagues and others respond to a doctor and his or her legal 'expertise' plays an important part in creating this schema.

Having briefly summarised the research findings, the next section draws some overall conclusions from this study; it then turns to this study's limitations, before ending with some recommendations.

3. Overall Conclusions

This study finds doctors seem to approach best interest decisions in two distinct ways. Doctors who tend to have long term relationships with a child and family (the softliners) seem to conceptualise best interest decision-making as a series of conversations with a wide spectrum of actors. Their approach seems to be child focused, considering the best interests of each individual child. Other doctors (hardliners) who tend to be called in to care for a child in a medical crisis and tend not to have a prior relationship with the child, seem to draw on heuristics to guide them as to when a disabled child should or should receive

¹¹²⁷ Ewick P, Silbey SS, (1999), '*Common Knowledge and Ideological Critique*', *Law and Society Rev*, 33, 1027; Ewick, P, Silbey, SS, (1998) *The Common Place of Law, Stories from everyday life*, The University of Chicago Press, Chicago

¹¹²⁸ Harding R, (2010), *Regulating Sexuality: Legal Consciousness in lesbian and gay lives*, Routledge, Abingdon

¹¹²⁹ Halliday, S, Kitzinger, C, Kitzinger, J (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74;

Halliday, S, Morgan, B (2013) I Fought the Law and the law Won? Legal Consciousness and the Critical Imagination, *Current Legal Problems*, vol. 66, pp.1-32

¹¹³⁰ Chapter nine, para 3.1, p. 364

treatment. No doubt in part due to the fact that they are acting in a medical crisis, the doctors in this study suggest these hardliner doctors, tend make decisions based on a 'type' of child, rather than on an individual. However, this study also found that the softliner doctors can be reluctant to share with hardliner doctors their more detailed knowledge of an individual child. The softliner doctors in this study and indeed some of the hardliners at the softliner end of the spectrum of positions,¹¹³¹ suggested that they routinely find themselves faced with a choice between prioritising a disabled child's best interests or prioritising the autonomy of a medical colleague's clinical judgment. The doctors suggest that when faced with this choice there can be a tendency, due to an ingrained culture of respect for colleague's clinical judgments and a wish to 'not rock the boat', that doctors will prioritise their colleague's judgment over a child's best interests.¹¹³²

The hardliner doctors seem to be very aware of the law when making their best interest decisions, although it was found that this was often awareness of the possible legal implications of their actions for them as doctors, rather than an awareness of the law as it relates to the child.¹¹³³ The softliners in contrast do not, other than in extreme circumstances, seem to conceive of the law as relevant when making their day-to-day best interests decisions for disabled children.¹¹³⁴ What is particularly interesting about these two approaches is that it is the softliners with their relational and communicative approach to best interest decisions, who seem to be aligning their best interest decisions most closely with their professional guidance. and the jurisprudence of the English High Court. In contrast, the hardliners who take what could be labelled as a

¹¹³¹ Chapter six, para 7, pp. 261-275

¹¹³² Ibid

¹¹³³ Chapter nine, para 3, pp. 361-378

¹¹³⁴ Chapter nine, para 2, pp. 353-361

much more legalistic approach, seem be further from making decisions in the way their guidance suggests they should do.

The finding that some doctors are not making best interest decisions in the way they are guided to do, raises the question whether there are enough checks and balances to protect severely disabled children when doctors are making these decisions. If doctors are following professional guidance, which in turns follows the jurisprudence of the English High Court, there can be some confidence that checks and balances are in place. However, this study has found that some doctors do not consult as widely, or consider an individual child's best interests in as much detail as they perhaps should.

As has been discussed, this study found that doctors seem to use proxies for best interests. It was found¹¹³⁵ that doctors define the factors they use when making best interest decisions very broadly, so that, for example, even factors such as prognosis can be defined to include broad non-clinical as well as clinical factors. Quality of life was particularly found to be used in this way.¹¹³⁶ It could be argued that defining factors broadly is a positive thing and in keeping with the jurisprudence of the English High Court judgments that:

'[b]est interests are not confined to best medical interests but embrace medical, social, emotional and welfare issues'.¹¹³⁷

However, this study found that a distinction could be drawn between softliners and hardliners in this regard. The softliners draw on wider 'social, emotional and welfare issues' by seeking information on these from, for example, a child's teacher, social worker or parents. The hardliners seem to make assumptions about non-clinical aspects of a child's life, such as, assuming a disabled child

¹¹³⁵ Chapter five, para 7, p. 236

¹¹³⁶ Chapter five, para 5, pp. 207-226

¹¹³⁷ *Re OT* [2009] EWHC 633 (Fam), para 98

does not attend school or cannot interact with his or her family.¹¹³⁸ It has been argued in this thesis that doctors can be seen to be acting in a quasi-judicial way.¹¹³⁹ The difference between the softliners and hardliners here make this point an important one. It is argued that it is appropriate for a decision-maker such as a judge to make decisions based on evidence the decision maker has gathered, but perhaps not to make decisions based on his or her own assumptions and presumptions.

This study has also identified a possible conflict here in the two lenses used in part two of this thesis to explore the doctors' best interest decisions. There does seem to be a conflict with the legal norm that best interest decisions should be wide-ranging and Kennedy's¹¹⁴⁰ concern that doctors should not make decisions on these wide-ranging issues. The only way to resolve this conflict is to recognise the quasi-judicial nature of best interest decision-making. A recommendation is made as how this might be addressed below.¹¹⁴¹

Exploring doctors best interest decisions through a legal consciousness lens also vividly illustrates how non-legal actors construct law in their every-day actions and interactions.

¹¹³⁸ Chapter six, para 7.2.3, p. 272

¹¹³⁹ Chapter five para 5.8, p. 225

¹¹⁴⁰ Kennedy, I, (1979) *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London

¹¹⁴¹ Chapter 10, para 5.2.1, p.400

4. Study limitations

Several limitations were identified at the start of this study and were listed in chapter three.¹¹⁴² Further additional limitations have been identified during the research and analysis process, as follows:

4.1 This study found that doctors who qualified in the 1990s, in general terms, seem to approach best interest decisions for disabled children differently from doctors who qualified in earlier decades. The research does not include any doctors who qualified after 1998, which would have allowed an assessment to be made as to whether this shift has continued. A larger pool of more recently-qualified doctors may have also made it possible to identify the reason for the apparent shift.

4.2 The three consultants who advised on the survey during the pilot had all advised taking a cautious approach when asking doctors about quality of life and futility. With hindsight, it seems these consultants may have been too cautious because the doctors in this study showed no reluctance to share their views. The three consultants were all neurologists, chosen to advise on the study because of their expertise in the care and treatment of disabled children. At that time, I was not aware, as was found during the study, that paediatricians from different sub-specialisms can conceptualise factors such as quality of life differently. I may have received different advice on discussing these factors, if the three paediatricians consulted had been from different, rather than the same, sub-specialism. Questions probing more deeply on futility and quality of life, could have potentially been included in the survey.

4.3 Due to the advice received from the advising consultants I also took a cautious approach in the early interviews, not probing the doctors too deeply.

¹¹⁴² Chapter three, para 16, pp.133-135

However, it became clear as the interviews progressed that the doctors had no concerns about discussing their and their colleagues best interest decision-making or being probed by me to give more detail. The later interviews therefore provided more data, depth and detail which was missing from the earlier interviews.

4.4 As was seen in chapter four,¹¹⁴³ an unexpectedly high number of doctors¹¹⁴⁴ with a personal experience of disability, including being parents of a disabled child were drawn to this study. This limited the study in two ways, firstly, the doctors reflections are likely to be atypical of paediatricians generally, as it seems likely that a doctor's personal experience of disability will impact on how a doctor treats a disabled child and that child's family. Indeed, the relevant doctors in this study confirmed they believed this to be the case. Secondly, it is a characteristic which is likely to make a doctor easily identifiable to colleagues. This meant this important characteristic could not be fully explored in this study, as it would have risked identifying the doctors involved.

Having briefly outlined the overall conclusions and additional limitations of this study, this chapter and the thesis now concludes with recommendations for further research and for potential changes in the law and practice when best interest decisions are being made for disabled children.

5. **Recommendations**

5.1 Research recommendations

Having completed this study, merit is seen in the following further research:

¹¹⁴³ Chapter four, para 4.9, pp.163-165

¹¹⁴⁴ 18% of the doctors in this survey reported being a parent of a disabled child.

5.1.1 A study exploring the same issues as this study with doctors who qualified since 2000 is recommended. This would hopefully be able to show whether the potential changes in the way doctors approach best interest decisions found in the doctors who qualified in the 1990s have continued.

5.1.2 This study only explored the role of doctors in best interest decisions for disabled children. Further studies exploring the role and experiences of nurses, parents and when possible the children, with those parties, is recommended. This has the potential to provide new insights into how best interest decisions are made and particularly how actively involved wider parties feel themselves to be.

5.1.3 Both hardliner and softliner doctors in this small study suggested that there may be barriers to cognitively impaired children (or children believed by the doctor to be cognitively impaired) accessing PICU treatment in some circumstances. Some of the doctors in this study suggested they think PICU treatment should have sometimes have been given in circumstances when it was withheld. A research study, such as a confidential inquiry by the National Confidential Inquiry into Patient Outcome and Death (NCEPOD), into this issue is recommended. In keeping with other NCEPOD inquiries, the research could identify the prevalence of this practice, if wider than the experience of the small number of doctors in this study, and identify whether this is a wider problem which needs addressing. If this is found, NCEPOD could then make appropriate recommendations.

5.1.4 This study touched on, but did not explore in any detail, the question of whether the courts can be too deferential to doctors by failing to lift the veil and unpack doctors' best interest decisions for disabled children. A particular question for a new study could perhaps be how the courts balance the two legal principles of the paramountcy of a child's best interests and the autonomy of a doctors' clinical judgment. This study has found that doctors can put a lot of weight on non-clinical factors when deciding for disabled children, which

perhaps throws new light on earlier decisions where judges have chosen not to question a doctors' clinical judgment.¹¹⁴⁵

5.1.5 Some doctors in this study suggested a reluctant to provide information they know about a child, which may be relevant to a best interest decision being made by a medical colleague. Research is recommended as to whether there is any merit in a duty of candour being introduced to encourage doctors to share information they have about patients with each other. This could parallel the duty of candour introduced in 2014¹¹⁴⁶ requiring health professionals to share information with patients and families. The research could explore whether the duty is needed, if it is, the best form for it and the likelihood of it improving information sharing between health professionals.

5.2 Recommendations for changes in the law and practice.

5.2.1 Mediation

Francis J, suggested in his final judgment in *GOSH v Gard*¹¹⁴⁷ that third party assistance, perhaps mediation, is needed to ensure that a child's best interests are fully explored when disagreements arise. He was talking about disagreements between parents and doctors, whereas the focus here is disagreements between doctors.

The reluctance of doctors to even voice their disagreement with colleagues' about best interest decisions may still be a barrier to mediation. However, if best interest meetings chaired by a suitably qualified neutral party were to become routine, doctors (and indeed other interested parties such as parents and nurses) may feel more empowered to share their views and expertise. It is recommended that the chair should not be a doctor, to move away from an

¹¹⁴⁵ Chapter five, pp.181-236

¹¹⁴⁶ Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 20

¹¹⁴⁷ Great Ormond Street Hospital v Yates & Gard [2017] EWHC 972 (Fam); para 130

assumption that best interest decisions are solely medical decisions and towards an universal premise, support by the law, that they are wide-ranging decisions that include clinical factors. However, in light of the resistance some doctors in this study showed towards external interference in their decision-making,¹¹⁴⁸ it might prove difficult to convince some doctors to take part in mediation. Nonetheless, it is envisaged that best interest mediation meetings chaired by a suitably qualified chair may help address several of the challenges to optimum best interest decision-making the doctors in this study identified.

5.2.2 Early exposure of medical students to disabled children

This and the final recommendation relates to doctors training, rather than to law or practice. The softliner doctors repeatedly raised concerns that their hardliner colleagues did not understand severely disabled children or their lives.¹¹⁴⁹ To help address this issue, it is recommended that medical students and junior doctors routinely have placements, (for example at a nursery or school for children with special needs) so that doctors in training who will later be treating disabled children get to know disabled children when they are well. Another advantage of such a placement is that it would encourage doctors in training to engage with other professional groups, in this case education staff, and recognise their knowledge and expertise. This would hopefully encourage doctors to draw on wider expertise later in their careers.

5.2.3 Disability Matters training

The RCPCH, together with the Department of Health and a consortium of child disability voluntary organisations have produced a virtual training platform 'Disability Matters'.¹¹⁵⁰ Produced jointly by health, third sector professional,

¹¹⁴⁸ Chapter nine, para 3, pp. 361-378

¹¹⁴⁹ Chapter six, para 7, pp.261-282

¹¹⁵⁰ Disability Matters web platform, <https://www.disabilitymatters.org.uk/> last accessed 30 January 2018

parents of disabled children and disabled children, it provides comprehensive training on all aspects of child disability, including many of the issues raised by doctors in this thesis. Its aims to improve professionals,' especially health professions understanding of disabled children's lives. Health trusts and other bodies use it to train staff. It is recommended that Disability Matters becomes part of every paediatrician's, including consultants, continuing professional development.

I would like to conclude this thesis by thanking all the doctors involved for being so generous with their time and reflections. Without you, this study would not have been possible.

Bibliography

- Aaron, HJ, Schwartz, WB, (1984) *The Painful Prescription, Rationing Hospital Care*, Brookings Institution Press, Washing DC
- Abrego, LJ, (2011) Legal consciousness of undocumented Latinos: Fear and stigma as barriers to claims-making for first-and 1.5-generation immigrants, *Law & Society Review*, 45(2), 337-370
- Albiston, CR, (2006) 'Legal Consciousness and Workplace Rights', chapter 3 in Fleury-Steiner B, Nielsen LB (Eds), *The New Civil Rights Research, A Constitutive Approach*, Ashgate Publishers Ltd, Oxford, p.55-76
- Albrecht, K.D. Seelman and M. Bury (Eds), (2001) *Handbook of Disability Studies*, Sage Publications, London
- Alkazi, R, (2011) 'Disability at the UN', in Dobhai,H, *Writing on Human Rights, Law and Society in India*, Socio-Legal Information Centre, Human Rights Law Network, Delhi
- Allen, KA, (2014) Parental decision-making for medical complex infants and children. An integrated literature review, *International Journal of Nursing Studies*, 51(9), 1289-1304
- Alston P, Porter S, Seymour J, (1995) *Children, Rights and the Law*, Clarendon Press, Oxford
- Armstrong D, Ashworth M, (2000) When questionnaire response rates do matter: a survey of general practitioners and their views of NHS changes, *Br J Gen Pract*, 50: 479–480
- Audit Commission, (2003) *Human Rights, Improving Public Service Delivery*, Audit Commission, London, para 12
- Bainham, A, (2005) *Children: The Modern Law*, (3rd Edition), Jordan Publishing Ltd, Bristol
- Ballatt J, Campling P, (2011) *Intelligent Kindness, reforming the culture of healthcare*, RCPsych Publishing London
- Barclay,S, Todd, C, Finlay, I, Grand ,G, Wyatt P, (2002) Not another questionnaire! Maximizing the response rate, predicting non-response and assessing non-response bias in postal questionnaire studies of GPs, *Family Practice* 19(1), 105-111 doi, 10.1093/fampra/19.1.105
- Basnett, I, (2001) 'Health Care Professionals and Their Attitudes Towards and Decisions Affecting Disabled People', in G.L. Albrecht, K.D. Seelman and M. Bury (Eds), *Handbook of Disability Studies*, Sage Publications, London, pp.450-467
- Baszanger, I, (1985) Professional socialization and social control: From medical students to general practitioners, *Social Science & Medicine*, 20(2), 133-143
- BBC News, (2000), *Landmark human rights law enforced*, BBC, 2nd October 2000
- Beauchamp TL, Childress JF, (2009) *Principles of Biomedical Ethics*, OUP, Oxford
- Bell, J, (2010) *Doing Your Research Project*, fifth edition, Open University Press, Maidenhead, pp. 54-55
- Berg, M, Mol, A (Eds), (1998) *Differences in Medicine*, Duke University Press, Durham & London
- Berger PL, Luckmann T, (1967) *The Social Construction of Reality*, Penguin Books, London

- Blackstone, A, Uggem, C, McLaughlin, H, (2009) Legal consciousness and responses to sexual harassment, *Law & society review*, 43(3), 631-668
- BMJ, (2016) *Assessment of learning difficulties and cognitive delay; Best Practice*, BMJ, London
- Brahams, D, Brahams, M, (1983) The Arthur case – a proposal for legislation, *Journal of Medical Ethics*, 9, 12-15
- Brazier M, Cave E, (2016) *Medicines, Patients and the Law*, Manchester Uni Press, Manchester
- Bridgeman, J, (2006), 'Caring for children with Severe Disabilities: Boundaries and Relational Rights', in Freeman M, Freeman, MDA, (Eds) *Children's Health and Children's Rights*, Martinus Nijhoff Publisher, Leiden
- British Medical Association, (2016) *Doctors' Titles Explained*, BMA, London
- Brotherton, A, Abbott, J, (2012) Mothers' process of decision making for gastrostomy placement. *Qualitative Health Research*, 22(5), 587–59
- Brush, EJ, (2015) Decision-Making shortcuts: The Good and the Bad, *New England Medical Journal*, Massachusetts
- Bryman A, (2015) *Social Research Methods*; Oxford University Press, Oxford, p. 175
- Bryman, A, (2012) *Social Research Methods*, 4th Edition, Oxford University Press, New York, pp.214-215
- Buchanan, AE, Brock DW, (1990) *Deciding for others: The ethics of surrogate decision making*, Cambridge University Press, Cambridge
- Bumiller, K, (1988) *The Civil Rights Society: The Social Construction of Victims*, John Hopkins University Press, Baltimore
- Byron, M, Cockshott, Z, Brownett, H, Ramkalwan, T, (2005) What does 'disability' mean for medical students? An exploration of the words medical students associate with the term 'disability', *Medical Education*, 39, 176-183, Blackwell Publishing Ltd, New Jersey
- Campbell, AG, Duff, RS, (1979) Authors' response to Richard Sherlock's commentary, *J Med Ethics* 5, 141-142
- Campbell, AGM, Duff, RS, (1979) 'Deciding the case of severely malformed or dying infants', *Journal of Medical Ethics*, 5(2), 65-67
- Campbell, J, Oliver, M, (2013) *Disability Politics*, Routledge, Abington
- Cantor, NL, (2005) *Making Medical Decisions for the Profoundly Mentally Disabled*, MIT, Massachusetts
- Care Quality Commission, (2016), '*Learning candour and accountability*' CQC a report which reviews the way the NHS investigates patient's deaths, including the deaths of disabled children, in England.
- Child Health Reviews UK, (2013), *Themed case reviews of mortality and morbidity in children and young people with epilepsy*, Child Health UK, London

- Christie, N, (1977) Conflict as Property, *The British Journal of Criminology*, Vol 17, Issue 1, pp. 1-15
- Clements L & Read J, (2008), 'Demonstrably Awful- The right to life and the selective non-treatment of disabled babies and young children', chapter 8 in Clements L & Read J, (Eds), *Disabled People and the Right to Life*, Routledge, Abington, pp.148-175
- Clements, L, Read, J, (2008) *Disabled People and the Right to Life*, Routledge, Abington
- Cockburn, J, Campbell, E, Gordon, J, Sanson-Fisher, R, (1988) Response bias in a study of general practice, *Fam Pract*, 15 18–23 and Ashworth M (2001) When response rates do matter, *Br Med J*, 322: 675
- Cohn A, (2016) Measuring quality of life, *BMJ*, 354: i3816
- Coker, M, Davis, JM, (2000) 'Disabled Children (Still) Invisible Under the Law, in Cooper, J, *Law Rights and Disability*, Jessica Kingsley Publishers, London
- Connolly, M, (2006), *Discrimination Law*, Sweet & Maxwell, London
- Cooper, D, (1995) Local Government Legal Consciousness in the shadow of Juridification, *Journal of Law and Society*, 22(4), 506-26
- Crisp R, Slote M, (2007) *Virtue Ethics*, Oxford University Press, Oxford
- Cuttini, M, Casotto, V, de Vonderweid, U, Garel, M, Kollee, LA, Saracci R, (2009) Neonatal end-of-life decisions and bioethical perspectives; *Early Human development*, vol. 85(10) pp. 521-525
- Cuttini, M, Nadai, M, Kaminski, M, Hansen, G, de Leeuw, Lenoir, S, Persson, J, et al, (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries, *The Lancet* 355.9221: 2112-2118
- Davies, M, (2017) '*Law Unlimited*,' Routledge, Abington, Oxford
- Davies P, (2013) *The Concise NHS Handbook 2013/14*, NHS Confederation, London
- de Vos, MA, Seeber AA, Gevers SK, Bos AP, Gevers, F, Willems, DL, (2015) Parents who wish no further treatment for their child, *Journal of Medical Ethics*, 41(2), 195-200
- Department of Health and Social Security, (1971) *Better services for the mentally handicapped*, Cm 4683, DHSS, London
- Disability Rights Commission, (2006) *Equal Treatment Closing the Gap*, DRC, London,
- Dixon -Wood M, et al (2016) *Culture and behavior in the English National Health Service: overview of lessons from a large multi-method study*, *BMJ Qual Saf* doi:10.1136/bmjqs-2013-001947, BMJ, London
- Duckworth SC, (1988) The effects of medical education on the attitudes of medical students towards disabled people, *Medical Education*, vol. 22, Issue 6, pp.501-505
- Dowie J, Elstein A, (2009) *Professional Judgment: A reader in clinical decision-making*, Cambridge Uni Press, Cambridge
- DWP, (2012) *Family Resources Survey United Kingdom 2010/2011*, Department of Work & Pensions, London
- Elliston, S, (2007) *The best interests of the child in healthcare*, Routledge, Abington

- Engel, DM, (1998) 'How Does Law Matter in the Constitution of Legal Consciousness?' in Garth, BG, Sarat, A, (Eds) *How Does Law Matter?* Northwestern University Press, Illinois
- English, R, (2007) *Human Rights Update: Glass v UK*, One Crown Office Row, London
- Ewick, P, Silbey, SS, (1992), 'Conformity, Contestation and Resistance: An Account of Legal Consciousness', *New England Law Review*, vol 26
- Ewick, P, Silbey, SS, (1999), 'Common Knowledge and Ideological Critique', *Law and Society Rev*, 33, 1027
- Ewick, P, Silbey, SS, (1998) *The Common Place of Law, Stories from everyday life*, The University of Chicago Press, Chicago
- Ferriman, A, (1981), Wide Support for Down's doctor, *The Times*, 10 November, The Times Digital Archive
- Field, D, Deeming, J, Smith, LK, (2016) Moral distress: an inevitable part of neonatal and paediatric intensive care? *archdischild* 310268
- Fitzsimmons, J, Barr O, (1997), A review of the reported attitudes of health and social care professionals towards people with learning disabilities: implications for education & further research, *Journal of Intellectual Disability*, vol. 1, Number 2, pp.57-64
- Fletcher, J, (1972), Indicators of Humanhood – A tentative profile of man, *The Hastings Centre Report*, 2(5) pp. 1-4
- Fleury-Steiner, B, Nielsen, LB, (2006) *The New Civil Rights Research, A Constitutive Approach*, Ashgate Publishers Ltd, Oxford
- Fortune, PM, (2006) Limiting and rationing treatment in Paediatric and neonatal intensive care, *Best Practice & Research Clinical Anaesthesiology*, vol. 20, Issue 4, pp.577-588
- Fox, CR, (2010) 'Medical Uncertainty Revisited' in Albrecht, GL, Fitzpatrick, R, Scrimshaw, SC, (Eds), *Handbook of Social Studies in Health and Medicine*, Sage Publications, Thousand Oaks
- Foxall, F, (2009) 'Ethical Issues', Chapter 4, in Jevon P (Ed) *Care of the Dying and Deceased Patient: A Practical Guide for Nurses*, John Wiley & Sons
- Francis, R, (2013), *Report of NHS Mid Staffordshire NHS Foundation Trust Public Inquiry*, The Stationery Office, London
- Francis, R, (2010) *Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005 – March 2009*, Vol 1, The Stationery Office, London
- Franklin, L, (2009) *Disabled Children and Health*, National Children's Bureau, London
- Fraser, LK, Miller, M, Hain, R, Norman, P, Aldridge, J, McKinney, PA & Parslow, RC, (2012) 'Rising national prevalence of life-limiting conditions in England', *Pediatrics*, vol. 129, no. 40, pp. 923-929
- French, S, (1988) Experience of disabled health and caring professionals, *Sociology of Health and Illness*, vol.10 Issue f2. pp.170-188
- Gampel, E, (2006) Does Professional Autonomy Protect Medical Futility Judgments? *Bioethics*, Vol. 20, Number 2, pp.92-104

- Garcia-Villegas, M, (2003) Symbolic Power without violence? Critical comments on legal consciousness studies, *International Journal of Semiotics of Law*, 16(4), 363-393
- Gee, DJ, Green, MA, (1982) The secret defence: a case for changing the law, *British Medical Journal*, (Clinical research ed), 284.6313 415
- Geertz, C, (1973) *'The Interpretation of Cultures'*, Basic Books, New York
- Gerhart K, Koziol-McLain J, Lowenstein S et al, (1994) Quality of life following spinal cord injury: Knowledge and attitudes of emergency care professionals, *Annals of Emergency Medicine*, vol 23, Issue 4, pp.807-812
- Gething, L, (1992) 'Judgements by health professionals of personal characteristics of people with a visible physical disability', *Social Science and Medicine*, 34(7), pp. 809-815
- Gething, I, (1994) The interaction with Disabled Person Scale, *Journal of Social Behaviour and Personality*, 9, pp. 23-42
- Gill, F, Stenfert Kroesa B, Rose J, (2002) General Practitioners attitudes to patients who have learning disabilities, *Psychological Medicine* 32 pp.1445-1455
- Gillis, J, (1997) When lifesaving treatment in children is not the answer, *BMJ* 315, pp. 1246-1247
- Gillon, R, (1985) An Introduction to philosophical medical ethics: the Arthur Case, *British Medical Journal* (clinical research ed), 290.6475 1117
- GMC, (2007) *'0-18 Guidance for all doctors'*, GMC, London
- GMC, (2011) *'The state of medical education and practice in the UK'*, GMC, London
- GMC, (2013) *'Good Medical Practice'*, GMC, London
- GMC, (2014) *Letter dated 14th January 2014 from Jackie Bell, Scottish Projects Officer GMC to Andrew Howlett, Assistant Clerk, Public Petitions Committee, Scottish Parliament*
- GMC, (2015) *'The state of medical education and practice in the UK: 2015'*, GMC, London
- GMC, (2015) *List of Registered Medical Practitioners – statistics*, GMC, London
- Graham, H, (2016) *Socioeconomic inequalities in health in the UK: Evidence on patterns and determinants, A short report for the Disability Rights Commission, DRC*, London
- Grey, E, Kennedy, I, (2016) *The Report of the Independent Review of Children's Cardiac Services in Bristol*, Bristol
- Guon, J, Wilfond, BS, Farlow, B, Bragg, T, Janvier, A, (2014) Our children are not a diagnosis. The experience of parents who continue their pregnancy after a prenatal diagnosis of trisomy 13 or 18, *American Journal of Medical Genetics*, Part A, 164 A (2), 308-318
- Groupman, J, (2008) *How Doctors Think*, Houghton Mifflin Company, New York
- Hafferty, F, Franks R, (1994) The Hidden Curriculum, Ethic Teaching and the Structure of Medical Education, *Academic Medicine*, Vol. 69(11), pp.861-871

- Haggett, E, (2001) *The Human Rights Act 1998 and Access to NHS Treatments and Services: A Practical Guide*, the Constitution Unit, School of Public Policy, UCL, London, p. 6
- Hall, C, (2000) *Rough Justice*, The Sunday Telegraph, 16th July, 2000
- Halliday, S, Kitzinger, C, Kitzinger, J, (2015) Law in everyday life and death: a socio-legal study of chronic disorders of consciousness, *Legal Studies*, vol. 35, No. 1, pp.55-74
- Halliday, S, Morgan, B, (2013) I Fought the Law and the law Won? Legal Consciousness and the Critical Imagination, *Current Legal Problems*, vol. 66, pp.1-32
- Halpern, J, (2001) *From Detached Concern to Empathy: Humanising Medical Practice*, Oxford Uni Press, Oxford
- Harding, R, (2006). "Dogs are 'registered', People shouldn't be' *Legal Consciousness and Lesbian and Gay Rights*", *Social and Legal Studies*, 15 (4),511-533
- Harding, R, (2010), *Regulating Sexuality: Legal Consciousness in lesbian and gay lives*, Routledge, Abingdon
- Harter, LM, Kirby, EL, (2004) Socializing medical students in an era of managed care: The ideological significance of standardized and virtual patients. *Communication Studies*, 55(1), 48-67
- Harter, LM, Krone, K J, (2001) Exploring the emergent identities of future physicians: Toward an understanding of the ideological socialization of osteopathic medical students. *Southern Journal of Communication*, 67(1), 66-83
- Harvey, WS, (2011) Strategies for conducting elite interviews, *Qualitative Research*, 11(4), 431-441
- Hayatt, MA, (2007) *Cancer Imagining: Lung & Breast Carcinomas*, Volume 1, Academic Press
- Haydon, D, Scraton, P, (2009) Children's rights: rhetoric and reality: Deena Haydon and Phil Scraton explore the deficit in effective implementation of children's rights in the UK, *Criminal Justice Matters* 76.1, pp.16-18
- Healthcare Commission, (2008) *State of Healthcare*, Healthcare Commission (now defunct)
- Hewson, B (2000) Why the human rights act matters to doctors, *BMJ*, 30;321(7264):780-1
- Hoffman, EA, (2003) Legal consciousness and dispute resolution: different disputing behavior at two similar taxicab companies, *Law Soc. Inq*, 28:691–718
- Herring, J, (2014) *Medical Law and Ethics*, Oxford Uni Press, Oxford
- Holt, A, (2010) Using the telephone for narrative interviewing: a research note, *Qualitative Research* 10(1), 113-121
- Hordon, L.D, (1993) The effect of Medical Training on Attitudes to Disabled People, *British Journal of Rheumatology*, 32: 151
- House of Commons, (1993) *Prioritising Health – The Debate about Health Care Rationing*, Research Paper, 93/49, Houses of Parliament, London

- House of Lords & House of Commons Joint Committee on Human Rights, (2004) *The Meaning of Public Authority under the Human Rights Act*, Seventh Report of session 2003-2004, HL paper 39, HC paper 382, 23rd February 2004
- Hursthouse, R, (1999) *On Virtue Ethics*, OUP, Oxford
- Huxtable, R, Forbes, K, (2004) 'Glass v UK: Maternal Instinct v Medical Opinion', *Child and Family Law Quarterly*, vol.16, No.3, pp.339-354
- Illich, I, (1995) *Limits to Medicine: Medical Nemesis: The Expropriation of Health*, Marion Boyars, London
- Irvine, DH, (2007) Everyone's Entitled to A Good Doctor, *Med J Aust*, vol. 186; no.5, 256-261
- Jaremba, U (2013) *National Judges as EU law judges: The Polish civil law system*, Martinus Nijhoff Publishers, Leiden
- Jackson, E, (2013) *Medical Law, Texts, Cases and Materials*, OUP, New York
- Jecker, NS, Pearlman, RA, (1992) Medical Futility: Who Decides? *Arch Intern Med*. 152(6), pp 1140-1144
- Jefferys, M, Elston, MA, (1989) The medical school as a social organization, *Medical education*, 23(3), 242-251
- Joseph-Williams. N, Elwyn, G, Edwards, A, (2014) Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared-decision making, *Patient Education & Counseling*, 94. 291-309
- Kafka, F, (2000) *The Trial*, Penguin Classics, London (first published 1925)
- Kamm, FM, (1993) *Morality, Mortality: Death and whom to save from it (Volume 1)*, OUP, Oxford
- Kelley, Clark, B, Brown, V, & Sitzia, J (2003) Good practice in the conduct and reporting of survey research, *International Journal for Quality in Health Care*, 15(3), 261-266
- Kennedy, D, (1980) 'Towards an Historical Understanding of Legal Consciousness: The Case of Classical Legal Thought in America, 1850-1940', in Spitzer S (Ed) *Research in Law and Sociology*, vol. 3, 3-24, JAI Press, Greenwich CT
- Kennedy, I, (1979) *What is a Medical Decision? Astor Lecture*, Middlesex Hospital Medical School, London
- Kennedy, I, (1981), *The Unmasking of Medicine*, George Allen & Unwin, London
- Kennedy, I, (2001), *Treat Me Right, Essays in Medical Law and Ethics*, OUP, Oxford
- Kennedy, I, (2010) *Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs*, Department of Health, London,
- Kennedy, I, Grubb, A, (2000), *Medical Law*, 3rd Edition, Butterworths, London
- Khan M, (2012) 'Teaching hospital versus district hospital', *BMJ*, London
- Kirkup B, (2015), *The Report of the Morecombe Bay Investigation*, The Stationery Office, London

- Klein, JG, (2005) Five pitfalls in decisions about diagnosis and prescribing, *BMJ*, 330: 781-784
- Kline, R, (2014) *The 'snowy white peaks' of the NHS: a survey of the discrimination in governance and leadership and the potential impact on patient care in London and England*, Middlesex University, London
- Kuhse, A, (1984) Modern Myth. That letting die is not the intentional causation of death: some reflections on the trial and acquittal of Dr Leonard Arthur, *Journal of Applied Philosophy*, 1.1, 21-38
- Lantos, JD, Meadows, W, (2006) *Neonatal Bioethics: the moral challenges of medical innovation*, The Johns Hopkins University Press, Baltimore, pp. 95-96
- Lantos, JD, Singer, PA, Walker, RM, (1989) The Illusion of Futility in Clinical Practice, *AM J Med* 87:81-84; & Ardagh, M (2000) Futility has no utility in resuscitation medicine, *Journal of medical ethics*, 26.5 396-399
- Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J, (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice, *Archives of Disease in Childhood* 2015;100: s1-s23
- Laurie G, (2006) 'The Autonomy of Others: Reflections on the Rise and Rise of Patient Choice in Contemporary Medical law' chapter 9, in Mclean, SAM, *First Do No Harm, Law Ethics and Healthcare*, Ashgate, Farnham, pp. 135-136
- Laurie GT, Harmon HE, Porter G, (2016) *Medical Futility*, Chapter 15 in Laurie GT, Harmon S, Porter G in Mason & McCall Smith's *Law & Medical Ethics* (10th edn), Oxford University Press, Oxford
- Lord St John of Fawsley, (2007), House of Lords Debate on Child Adoption, *Hansard*, Column 236; 21st January 2007
- Lord Walton of Detchant, (1994) 'Medical Ethics Select Committee Report', House of Lords Debate, *Hansard*, vol 554 cc1344-412, House of Lords, London
- Maclean, AR, (2000) 'The Human Rights Act 1998 and the Individual's Right to Treatment,' *Medical Law International*, vol 4, Issue 3-4, pp 245-276,
- Marshall, AM, Barclay, S, (2003) In their own words: how ordinary people construct the legal world, *Law & Social Inquiry*, 28(3), 617-628
- Marshall, J, Haines, A (1990) Survey of the teaching of disability and rehabilitation to medical undergraduates in the UK, *Medical Education*, 24, pp. 528-530
- Martin G, (2014) 'Caring for patients with intellectual disabilities', chapter 9 in Gill, P, Wright N, Brew I (Eds), *Working with vulnerable groups: A clinical handbook for GPs; Royal College of General Practitioners*, RCGP, London
- Martin, HI, Rowell, MM, Reid, SM, Marks, MK, Reddihough, D, (2005) Cerebral palsy: What do medical students know and believe?' *J. Paediatr. Child Health*, 41, pp. 43-47
- Mason, J, (2011) 'Semi-structured Interview', in Lewis-Bench, MS, Bryman, A, Futing, L, (eds), *The SAGE Encyclopaedia of Social Science Research Methods*, SAGE, Thousand Oaks
- Mason, JK, Laurie, GT (2013) *Mason and McCall Smith's Law and Medical Ethics*, (9th Edition), Oxford University Press, Oxford

- Mathieu, B, (2006), *The Right to life*, Council of Europe Publishing, Strasbourg
- Mazar, (2015) *Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015*, NHS England, London
- Macintyre, A, (2007) *After Virtue: A Study in Moral Theory*, (Third Edition), Notre Dame, Indiana
- McClatchey, KD, (2002) *Clinical Laboratory Medicine*, Lippincott, Williams & Wilkins,
 McDowell, L (1998) Elites in the City of London: some methodological considerations, *Environment and Planning*, 30(12), 2133-2146
- McFarlane, A, Mugford, M, (2012) 'Epidemiology' in J Rennie (Ed), *Rennie & Robertson's Textbook of Neonatology*, Churchill, London
- McHaffie, H, Fowlie, PW, (1998) Withdrawing and withholding treatment: Comments on new guidelines, *Archives of Disease of Childhood*, vol.79, Issue 1, pp. 1-5
- McIntosh, N, (2017) 'Ethics', chapter 14 in Craft A & Dodd K (Eds), *From An Association to A Royal College: The History of the British Paediatric Association and Royal College of Paediatrics and Child Health 1988-20016*, Springer, New York
- McLaughlin, J, (2006) 'Conceptualising Intensive Caring Activities: The Changing Lives of Families with Young Disabled Children' 11(1) *Sociological Research Online*
- Mclean, SAM, Williamson, L, (2007) *Impairment and Disability: Law and ethics at the beginning and end of life*, Routledge-Cavendish, Oxford
- Mebane, EW, Oman, RF, Kroonen, LT, Goldstein, MK, (1999) The Influence of Physician Race, Age, and Gender on Physician Attitudes Toward Advance Care Directives and Preferences for End-Of-Life Decision-Making, *Journal of the American Geriatrics Society*, 47(5), 579-591
- Meehan E, Freed GI, Reid SM, Williams K, Sewell JR, Rawicki B & Reddihough DS, (2015) 'Tertiary paediatric admissions in children and young people with cerebral palsy', *Child: care, health and development*, vol. 41, no. 6, pp. 928-937
- Mencap, (2012) *Death by Indifference: 74 deaths and counting*, Mencap, London
- Merry, S. E. (1992). *Culture, power, and the discourse of law*. *NYL Sch. L. Rev.*, 37, 209
- Merry, SE, (1990) *Getting Justice and Getting Even: Legal Consciousness Among Working Class Americans*, Chicago Univ. Chicago Press, Chicago
- Mezey, N, (2001) Out of the ordinary: law, power, culture, and the commonplace, *Law & Social Inquiry*, 26(1), 145-167
- Montgomery J, (2015) *Children and Clinical Research: ethical issues*, Nuffield Council of Bioethics, London
- Michael, J, (2008) *Healthcare for all*, Learning Disabilities Observatory, London
- Michael, J, Richardson, A, et al, (2008), 'Healthcarefor all: The Independent Inquiry into Access for Healthcare for People with Learning Disabilities', *Tizard Learning Disability Review*, 13 (4), pp.28-34

- Mitchell, KR, Hayes, M, Gordon, J & Wallis, B, (1984), An Investigation of the Attitudes of Medical Students to Physically Disabled People, *Medical Education*, 18: 21-23
- Myrdal, G, (1969) *Objectivity in social research*, Pantheon, New York
- NHS Commissioning Board, (2015) *Safeguarding Policy* NHS England, London
- NHS Health Research Authority, (2011), *Governance Arrangements for Research Ethics Committees*, NHS HRA, London
- NHS Lothians, (2011) *Equality and Diversity Policy*, NHS Lothian, Edinburgh
- NHS Medical Directorate, (2009), *A Junior Doctor's Guide to the NHS*, Department of Health, London
- NICE, (2016) *End of life care for infants, children and young people with life-limiting conditions: planning and management*, NG61
- NICE, (2016) *End of life care for infants, children and young people with life-limiting conditions: planning and management*, NG61, NICE, London
- NICE, (2017) *End of life care for infants, children and young people, Quality Standard*
- Nielsen, B, (2000) Situating Legal consciousness: Experiences and Attitudes of Ordinary Citizens About Law and Street Harassment *Law and Society Review*, p.1058
- Nimmon, L, Stenfors-Hayes, T, (2016) The 'Handling' of power in the physician-patient encounter: perceptions from experienced physicians. *BMC medical education*, 16(1)
- Nuffield Council, (2006) *Critical Care Decisions in fetal and neonatal medicine: ethical issues*. Nuffield Council on Bioethics, London
- Office for the United Nations High Commissioner for Human Rights, (2005) *The United Nations Human Rights Treaty System: An Introduction to the core human rights treaties and the treaty bodies*, Fact Sheet Number 30, United Nations; Geneva
- OUP, *Oxford Concise Medical Dictionary*, (2014) Oxford University Press, Oxford
- Paediatric Intensive Care Audit Network, (2011) *Annual report of the Paediatric Intensive Care Audit Network, January 2008- December 2010, Summary Report*, Universities of Leeds and Leicester
- Paris, M.J, (1993) 'Attitudes of medical students & healthcare professionals towards people with disabilities', *Archives of Physical Medicine and Rehabilitation*, 74 (8), pp. 818-825
- Parliamentary and Health Service Ombudsman, (2009), *Six Lives: the provision of public services to people with learning disabilities*, PHSO, London
- Parsons, JA, Warnecke, RB, Czaja, RF, Barnsley, J, Kaluzny, A, (1994) Factors associated with response rates in a national survey of primary care physicians, *Evaluation Review*, 18(6), 756-766
- Parsons, S, Lewis A, Ellins, S, (2009) The views and experiences of parents of children with autistic spectrum disorders about educational provision: comparisons with parents of children with other disabilities from an online survey, *European Journal of Special Education Needs*, vol.24, Issue 1, pp.37-58

Pearson, C, Watson, N, (2007) Tackling Disability Discrimination in the United Kingdom: the British Disability Discrimination Act, *Journal of Law and Policy*, 23: 95-120

Phillips, DC, (1990) 'Subjectivity and Objectivity: An Objective Inquiry', in Eisner, EW, & Peshkin, A, (Eds), *Education: Qualitative Inquiry In The Continuing Debate*, Teachers College Press, New York

Price J, McAlinden O, (2018) *Essential of Nursing Children and Young People*, Sage Publications, London

Priest, N, Esmail, A, Williams, DR, Sprague, Norman, F, Smart, Norman, L, (2015) Promoting equality for ethnic minority NHS staff –what works?', *BMJ* 2015: 351: h3297

Quin G, Degener T, (2002) *Human Rights and Disability*, OHCHR, New York

RCPCH, (2004) *Withholding Life Sustaining Treatment in Children, A Framework for Practice, second edition*, RCPCH, London

RCPCH, (2011) *RCPCH Medical Workforce Census for 2009*, RCPCH, London

RCPCH, (2013) *RCPCH Medical Workforce Census for 2011*, RCPCH, London

RCPCH, (2014), *RCPCH Medical Workforce Census 2013*, RCPCH, London

RCPCH, (1997) *Withholding and Withdrawing Life Saving Treatment, a Framework for Practice 1997*, RCPCH, London

RCPCH, (2013), *Child Health Reviews – UK, Clinical Outcome Review Programme, Overview of child deaths in the four UK countries*, RCPCH, London

RCPCH, (2016), *Paediatric Sub-Specialty Glossary*, RCPCH, London

Rennie, JM, Leigh B, (2008) The legal framework for end-of-life decisions in the UK, *Seminars in Fetal & Neonatal Medicine*, 13, 296-300

Richter, J, Eisemann, M, Zgonnikova, E, (2001) Doctors' authoritarianism in end-of-life treatment decisions. A comparison between Russia, Sweden and Germany. *Journal of Medical Ethics*, 27(3), 186-191

Rose, N, Kent, S, et al, (2010) Health professional's attitudes and emotions towards working with adults with intellectual disability and mental ill health, *Journal of Intellectual Disability*, 56, 854–864

Ross, T, (2012)'Disabled patients dying due to institutionalised discrimination in NHS', *The Telegraph*, 3rd January 2012

Rossmann, GB, (2011) *Learning in the Field: An Introduction to Qualitative Research*, Third Edition, Sage Publications, Thousand Oaks

Royal College of Paediatrics and Child Health & University College London, (2013) *Child Health Reviews- UK – Overview of child death in the four UK countries*, RCPCH, London

Royal College of Paediatrics and Child Health, (2016) *What is Paediatrics?* RCPCH, London

Sarat, A, (1990) 'The law is all over': power, resistance and the legal consciousness of the welfare poor, *Yale J. Law Humanit.* 2:343– 79

- Sarat A, Kearns TR, (1998) *Law in Everyday Life*, Uni of Michigan Press, Michigan
- Scottish Government, (2002) 'Voice of the Child' Under the Children (Scotland) Act 1995', *Mapping Paper, Concluding thoughts - Issues and questions*, chapter seven, vol. 1, Scottish Government, Edinburgh
- Shakespeare, T, (2016) 'The Social Model of Disability', in David LJ, (Ed), *The Disabilities Studies Reader*, chapter 13, Taylor & Francis, Abington, p. 196
- Shearer, A, (1984) *Everybody's Ethics: What future for handicapped babies?*, The Campaign for Mentally Handicapped People, London
- Sidebottom, P, (2013) *Child Health Reviews UK: Clinical Outcomes Review Programme, RCPCH, London*
- Silbey, SS, (2005) 'After legal consciousness', *Annu. Rev. Law Soc. Sci.*, 1, 323-368
- Slote, M, (2007) *The Ethics of Care and Empathy*, Routledge, Abington
- Smith, Hamilton, S, Grimard, L J, (2014) 'The emotional and psychological impact on radiation therapists of treating children', *Journal of Medical Imaging and Radiation Sciences*, 45(3), 276-282
- Smith, J, Cheater, F, Bekker, H, (2013) 'Parents experiences of living with a child with a long-term condition: a rapid structured review of the literature', *Health Expectations*, vol. 18, issue 4, 452-474
- Sobal, J, DeForge, BR, Ferentz, K. S, Muncie Jr, H., Valente, C M, Levine, DM, (1990) 'Physician responses to multiple questionnaire mailings', *Evaluation Review*, 14(6), 711-722
- Steele, R, Siden, H, Cadell, S et al, (2014), 'Charting the territory: symptoms and functional assessment in children with progressive non-curable conditions', *Archdischild*, 99(8)
- Stephens N, (2007) 'Collecting data from elites and ultra-elites: telephone and face to face interviews with macroeconomists', *Qualitative Research*, vol. 7(2), SAGE Publications, London, 203-216
- Strong, PM, (1979) *The Ceremonial Order of the Clinic*, Routledge, London,
- Sturges JE, Hanrahan KJ, (2004) 'Comparing telephone and face to face qualitative interviewing: a research note', *Qualitative Research*, vol 4(1) SAGE Publications, London, 107-118
- The Bristol Royal Infirmary Inquiry, (2001), *The Inquiry into the management of care of children receiving complex heart surgery at the Bristol Royal Infirmary, Final Report*, Bristol Royal Infirmary Inquiry, Bristol
- The Mid-Staffordshire NHS Foundation Trust Public Inquiry, (2013) *Report of the Mid-Staffordshire NHS Foundation Trust Public Inquiry*, volume 3, HC898-111, The Stationery Office, London
- The Sutton Trust, (2009) *The Educational Background of Leading Lawyers, Journalists, Vice Chancellors, Politicians, Medics and Chief Executives*, The Sutton Trust, Sutton
- Tracy, J, Iacono, T, (2008) 'People with developmental disabilities teaching medical students – Does it make a difference?', *Journal of Intellectual and Developmental Disability*, Vol.33 (4), pp. 345-348

Tracy, J, McDonald, R, (2015) Health and Disability: Partnership in Health care, *Journal of Applied Research in Intellectual Disabilities*, 28(1), pp.22-32

UNCRC, (2002) *General Comment No.2, The role of independent human rights institutions in the promotion and protection of the rights of the child*, CRC/GC/2002, United Nations, Geneva

UNCRC, (2008) *Committee on the Right of the Child, Consideration of Reports Submitted by State Parties Under Article 44 of the Convention, third and fourth periodic reports of States parties due in 2007 United Kingdom of Great Britain and Northern Ireland*, UN, Geneva

UNCRPD, (2017) *Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland*, CRPD/C/GBR/CO/1, United Nations, Geneva

United Nations Convention on the Rights of the Child, (2008) *Committee on the Rights of the Child; Consideration of reports submitted by state parties under Article 44 of the Convention; third and fourth periodic reports of States parties due in 2007 United Kingdom of Great Britain and Northern Ireland*, CRC/GBR/4, United Nations, Geneva

Vincent C, (2010), *Patient Safety*, 2nd Edition, BMJ Books, London

Warwick, C, Perera, L, Murdoch, E, Nicholl, R, (2011) Guidance for withdrawal and withholding of intensive care as part of neonatal end-of –life care, *British Medical Bulletin*, vol 98(1) pp.99-113

Whiteneck, G, (1989) Long-term outlook for persons with high quadriplegia, in Whiteneck G, Adler C, Carter RE et al (Eds) *The Management of High Quadriplegia*, Demos Publications, New York

Whiting. M, (2012) Impact, meaning and need for help and support: The experience of parents caring for children with disabilities, life threatening illnesses or technology dependence, *Journal of Child Health*, 17(1), 92-108

Wicks E, (2007) *Human Rights and Healthcare*, Hart Publishing, Portland

Wilkinson D, (2013) *Death or Disability? The ‘Carmentis Machine’ and decision-making for critically ill children*. Oxford University Press, Oxford

Wilkinson, D, Truog, RD, (2013) The luck of the draw: physician-related variability in end-of-life decision-making in intensive care, *Intensive Care Medicine*, 39, 1128-1132

Williamson, A E. Ayres, R, (2013) *A core curriculum for learning about health inequalities in UK undergraduate medicine*, RCGP, London

World Health Organisation; (1997) *Measuring Quality of Life: WHO/MSA/MNH/PSF/97.4*; WHO, Geneva

Yuker, HE, Block, J. R, Young, JH, (1966) *The measurement of attitude toward disabled persons*, Human Resources Study No. 7, Human Resources Center, Albertson

Zaal-Schuller, IH, Willems DC, Ewals, FVPM, van Goudoever, J.B, de Vos MA, (2016) How parents and physicians experienced end-of-life decision-making for children with profound intellectual & multiple disabilities, *Research in Developmental Disabilities*, vol. 59, pp 293-293

Appendices

1. Schedule of figures included in thesis
2. Ethics letter from South East Scotland Research Ethics Service
3. Letter to doctors inviting participation in survey
4. Study survey
5. Letter to doctors confirming interview
6. Sample interview questions

Appendix 1

Schedule of Figures included in thesis

<u>Figure No</u>	<u>Title</u>	<u>Page</u>
1	Survey requests issued and potential population	115
2	Survey response rate	121
3	Nvivo codes based on research questions and sub-specialisms	125
4	Interviewee statistics	127
5	Regions interviewees employed, (current and past)	127
6	Sub-specialties, gender and age band of interviewees	128
7	Nvivo Codes: categories of legal consciousness	132
8	Characteristics attributed to Ewick and Silbey's schema	133
9	Characteristics attributed to Halliday et al's schema	133
10	Characteristics attributed to Harding's schema	133
11	Paragraphs 12-13, GMC 0-18 Guidance (Source GMC)	144
12	Professional and demographic profiles of study survey participants	149
13	Places of work of participants at date of survey	152
14	Health regions in which participants have worked	153
15	University undergraduate medical training completed	154
16	Participants' paediatric sub-specialties	157
17	Years experience since registration as medical doctor	158
18	Participants' age	159
19	Participants' ethnic origin	161
20	Participants' gender	162
21	Participants' parental status	163
22	Participants' personal experience of disability	164
23	Participants' religion or faith	166
24	Factors doctors find most difficult when making difficult decisions for disabled children	173
25	Factors doctors cite when asked 'What are the main factors you consider when making these decisions?'	178
26	Use of prognosis by sub-specialties	187
27	Use of clinical and non-clinical factors when assessing prognosis	189
28	Use of prognosis and gender	190

29	Doctors' use of clinical and non-clinical factors when assessing prognosis	190
30	Use of prognosis and personal experience of disability	191
31	Use of clinical and non-clinical factors when assessing prognosis by the doctor's personal experience of disability	193
32	Use of prognosis and duration of practice	194
33	Use of clinical and non-clinical factors when assessing prognosis by the doctor's decade of qualification	195
34	Use of prognosis and religious faith	196
35	Use of clinical and non-clinical factors when assessing prognosis by the doctor's religious faith	197
36	Use of futility and sub-specialties	202
37	Use of futility and gender	203
38	Use of futility and personal experience of disability	204
39	Use of futility and duration of practice	205
40	Futility and a doctor's faith	207
41	Factors doctors cite as relevant to quality of life assessments	213
42	Use of quality of life and sub-specialties	214
43	Use of clinical and non-clinical factors in doctors' quality of life assessments	215
44	Use of quality of life and gender	216
45	Use of clinical and non-clinical factors in doctors' quality of life assessments	217
46	Quality of life and personal experience of disability	218
47	Use of clinical and non-clinical factors in doctors' quality of life assessments & personal experience of disability	219
48	Use of quality of life and duration of practice	221
49	Use of clinical and non-clinical factors in doctors' quality of life	222
50	Use of quality of life and a doctor's faith	223
51	Use of clinical and non-clinical factors in doctors' quality of life assessments & a doctor's faith	224
52	Use of a child's cognitive ability and sub-specialties	229
53	Use of a child's cognitive ability and gender	230
54	Use of a child's cognitive ability and personal experience of disability	232
55	Use of a child's cognitive ability and duration of practice	233
56	Use of a child's cognitive ability and religious faith	234
57	Doctors who were interviewed	239

58	Legal and ethical education while at medical school	328
59	Post-qualification legal and ethical training	329
60	Education in law and ethics doctors have received pre and post qualification	331
61	Education and training in law and ethic received by decade of qualification	332
62	Interviewed doctors' legal education and whether the doctor's responses appear to show a hardliner or softliner approach	349



Appendix 2

Letter from South East Scotland Research Ethics Service

South East Scotland Research Ethics Service

Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Tel: 0131 536 9067
Fax: 0131 536 9346

NHS
Lothian

Name: Zoe Picton-Howell
Address: 
Edinburgh
EH 

Edinburgh 13/04/2010
Your Ref:
Our Ref: 10/S1101/14
Enquiries to: Alex Bailey
Extension:
Direct Line: 0131 536 9050
Email: alex.bailey@nhslothian.scot.nhs.uk

Dear Zoe,

Full title of project: Difficult Medical Decision making for disabled children in the UK

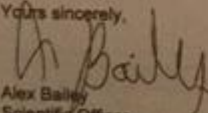
You have sought advice from the South East Scotland Research Ethics Service on the above project. This has been considered by the Scientific Officer and you are advised that, based on the submitted documentation (IRAS application form), it does not need NHS ethical review under the terms of the Governance Arrangements for Research Ethics Committees in the UK. The advice is based on the following:

- The project is an opinion survey seeking the views of NHS staff on a healthcare issue.
- The project is an opinion survey seeking the views of NHS staff on service delivery.

If this project is being conducted within NHS Lothian you should inform the relevant local Quality Improvement Team(s).

This letter should not be interpreted as giving a form of ethical approval or any endorsement of the project, but it may be provided to a journal or other body as evidence that ethical approval is not required under NHS research governance arrangements. However, if you, your sponsor/funder or any NHS organisation feels that the project should be managed as research and/or that ethical review by a NHS REC is essential, please write setting out your reasons and we will be pleased to consider further. Where NHS organisations have clarified that a project is not to be managed as research, the Research Governance Framework states that it should not be presented as research within the NHS.

You should retain a copy of this letter with your project file as evidence that you have sought advice from the South East Scotland Research Ethics Service.

Yours sincerely,

Alex Bailey
Scientific Officer
South East Scotland Research Ethics Service

Enclosure: NRES leaflet - "Defining Research"

Appendix 3

Letter to potential survey participants

Dear Dr X

I am a PhD researcher at Edinburgh University undertaking research into difficult medical decision making for disabled children in the UK. As part of that research I have produced, in consultation with my academic supervisors and with consultant paediatric specialists and nurses here in Scotland, an on-line surveys for doctors asking about difficult medical decision making concerning disabled children. I am interested to learn how doctors make difficult medical decisions involving disabled children and what factors influence these decisions. The surveys are intended for doctors working with children in the UK.

I wish to canvass the views and experience of doctors from a number of paediatric specialities and would be extremely interested in your views as an experienced paediatric specialist. The surveys have been given ethical clearance by Edinburgh University and the South East Scotland Research Ethics Service which reviewed the surveys for the NHS, has informed me that this project "does not need NHS ethical review under the terms of the Governance Arrangements for Research Ethics Committees in the UK."

The paediatric consultants and nurses with whom I have consulted in developing the survey felt that the questions raised are important ones, so I very much hope you will be able to complete the survey. Please also feel free to forward details of the surveys to medical colleagues. I would also be interested in the views of Registrars and junior doctors, as well as the views of consultants, so please feel free to forward details of the survey to junior colleagues as well as to fellow consultants.

If you wish to know more about my PhD, you can read this at <http://www.law.ed.ac.uk/research/students/133.aspx>

I am also very happy to answer any questions you may have.

The on-line survey can be accessed here

<http://www.survey.ed.ac.uk/medicaldecisionsdoctors/>

Sincere thanks for taking the time to read this email and for any for any assistance you are able to give with this project.

Yours sincerely

Appendix 4

Study Survey

Difficult Medical Decision Making for the UK's Disabled Children

Page 1: Welcome

Welcome to the Difficult Decision Making for the UK's Disabled Children Survey. This survey aims to collect data for use in a PhD study examining difficult medical decision making for the UK's disabled children.

You can choose to give your name or you can choose to complete this survey anonymously. The primary purpose of this study is to ascertain how doctors make difficult medical decisions for disabled children in reality and what influences those decisions.

In answering this survey, you are asked to reflect on your own experience of difficult medical decision making for disabled children.

For the purpose of this study the term "disabled children" is used to describe children with chronic health conditions and physical and sometimes sensory and cognitive impairments. These children will often have some level of neurological impairment, will often be described as having "life limiting" conditions, although they will not necessarily be terminally ill.

THE RESEARCHER WOULD WELCOME THE OPPORTUNITY TO DISCUSS IN PERSON WITH A SAMPLE OF PARTICIPANTS FROM THIS STUDY THE ISSUES RAISED IN THIS SURVEY. IF YOU WOULD BE HAPPY TO MEET WITH THE RESEARCHER TO DISCUSS THE ISSUES RAISED IN THIS SURVEY IN GREATER DETAIL, PLEASE PROVIDE YOUR NAME AND CONTACT DETAILS WHERE INDICATED IN THE BODY OF THE SURVEY. YOUR NAME AND CONTACT DETAILS WILL BE KEPT CONFIDENTIAL, WILL NOT BE PUBLISHED AND WILL ONLY BE ACCESSIBLE TO THE RESEARCHER.

The survey can be saved part way through and takes around 45 minutes to complete.

THIS SURVEY HAS ETHICAL APPROVAL FROM THE UNIVERSITY OF EDINBURGH AND HAS BEEN APPROVED AS NOT NEEDING "NHS ETHICAL REVIEW UNDER THE TERMS OF THE GOVERNANCE ARRANGEMENTS FOR RESEARCH ETHICS COMMITTEES IN THE UK" BY THE SOUTH EAST SCOTLAND RESEARCH ETHICS SERVICE.

NOTE that once you have clicked on the CONTINUE button at the bottom of each page you can not return to review or amend that page

The researcher can be contacted by email at [email provided]

Data Protection

All data collected in this survey will be held securely. Participants' names and place of work will not be published.

Participants will be referred to in all published data by a code and reference may be made to a

participant's specialism, sex and NHS region (for example Doc001 a female neurologist from London or Doc 002 a male respiratory specialist from Wales).

Aggregate data may be retained to benchmark future surveys.

Participants may remain anonymous, but do please provide your name and contact details if you are willing to assist further with this research project, or if you would like to receive a summary of the research findings.

Cookies, personal data stored by your Web browser, are not used in this survey.

Background Information

1. Surname Name

You can choose to remain anonymous and complete this survey. However, if you would be willing to participate further in this research or would like to receive a summary of the study findings, please provide your full name and contact details. Your name and contact details will be kept confidential and will NOT be used other than to contact you to arrange further discussion or to send you details of the study findings.

2. First Name

3. Contact email address

4. Postal Address

5. Contact telephone number

6. Would you be willing to discuss the issues raised in this survey in more detail with the researcher in person?

YES/NO

7. Would you like to receive a summary report of the findings of this research once the research has been completed?

YES/NO

8. Current specialism

Please select
Community Paediatrics/ Endocrinology/ General Paediatrics/ Intensive Care/ Neurology/
Respiratory Medicine/. Other
If you selected Other, please specify:

9. Why did you choose to specialise in this area of medicine?

Training and Current Post

The following section asks you questions about your training and current position.

10. Current Post

11. Number of years in current post

12. Professional Qualifications

13. At which university/universities did you undertake medical training?

14. In which year did you qualify as a doctor?

15. Of which professional bodies are you a member?

For example, Royal College of Paediatrics and Child Health; British Paediatric Neurology Association; The Intensive Care Society etc

16. In which NHS regions have you worked?

Eastern/London/North & Yorkshire/North West/Northern Ireland/Scotland/South East/South West/Trent/Wales/West Midlands/Other

If you selected Other, please specify:

17. What impact, if any, do you think your training had on the way you now approach difficult medical decisions for disabled children?

18. What impact, if any, do you think colleagues you have worked with in the past or currently work with have had on the way you approach difficult decision making for disabled children?

Child Dependant Factors

This section asks you about the child dependant factors you consider when making difficult medical decisions concerning disabled children.

Throughout this study the child or children under consideration are disabled children with chronic health conditions, with physical and sometimes sensory and cognitive impairments. The children under consideration will often have some level of neurological impairment; will often be described as having "life limiting" conditions, although they will not necessarily be terminally ill.

19. What sort of difficult decisions do you find yourself making when dealing with disabled children?

20. What aspect of these decisions do you find most difficult?

21. What are the main factors which you consider when making these decisions?

22. Do you have a written framework for making these decisions?

Please select

YES/NO

23. If yes, who created the framework?

For example, is the framework one you have produced yourself; was it produced by you with colleagues; is it a standard framework used throughout your institution; is it a framework produced by a professional body such as a Royal College or is it a framework used internationally? There may be other possibilities.

24. What part does a child's medical prognosis play?

25. What factors do you consider when making a medical prognosis for an individual child with disabilities?

26. What factors make a medical prognosis harder or easier?

27. How confident do you feel that you are able to make an accurate prognosis for an individual

child with disabilities?

very confident/confident/moderately confident/somewhat lacking in confidence/not at all confident

28. What part does futility play in difficult medical decisions for disabled children?

29. What impact does a child's quality of life have on these decisions?

30. If you assess a child's quality of life, what factors do you feel are relevant to this assessment?

31. What part does a child's cognitive ability play in these assessments?

32. If you make such an assessment, how do you make an assessment of a disabled child's level of cognitive ability?

33. If you make assessments of disabled children's cognitive ability, how confident do you feel that you are able to make an accurate assessment of an individual disabled child's cognitive ability?

very confident/confident/moderately confident/somewhat lacking in confidence/not at all confidence/assessment not made

34. With whom do you consult when making difficult medical decisions about an individual disabled child?

35. Do you ever find you have a difference of opinion with colleagues when making difficult medical decisions concerning disabled children?

YES/NO

36. If you do ever have a difference of opinion with colleagues, how do you reach a resolution?

37. How relevant are a child's personal circumstances and home environment when making these sorts of decisions?

38. What is the role of the medics in these types of difficult medical decisions?

39. What is the role of the nursing team in this type of difficult medical decisions?

40. What is the role of the parents or the child's primary care giver(s) in these types of decisions?

41. What is the role of the child in these types of difficult medical decisions?

Please use the box below to add any further comments or observations you may have about your experience of making difficult medical decisions concerning disabled children.

The Law, Rights and Ethics

42. What influence does the law have on your medical decision making for disabled children?

43. What training (if any) did you receive in medical law, pre-qualification?

44. What training (if any) did you receive in medical law post qualification?

45. Do you ever consult with your health authority lawyers?

YES/NO

46. If yes, in what sort circumstances?

47. If you ever do consult with your health authority lawyers, how helpful do you find the advice they give you?

not at all helpful/somewhat unhelpful/moderately helpful/helpful/very helpful

48. The UK is said to be becoming a more and more litigious country, have you noticed this impacting on your practise and if so how?

49. Have you ever acted as an expert witness?

Please select
YES/NO

50. If yes, in what type of cases?

51. If yes, has this had an impact on your own practise, and if so how?

52. What relevance (if any) do you think the law has in the context of these types of difficult medical decisions?

53. What training (if any) did you receive in human rights pre-qualification?

54. What training (if any) did you receive in human rights Post qualification?

55. Are a child's human rights a factor you consciously consider when making difficult medical decisions for a disabled child?

Please select
YES/NO

56. What relevance (if any) do you think human rights have in the context of these types of difficult medical decisions?

57. What training (if any) did you receive in ethics, pre-qualification?

58. Post qualification

59. What relevance (if any) do you think ethics have in the context of these types of difficult medical decisions for disabled children?

60. Where would you turn to for support if you were looking for ethical guidance?

61. Are there any areas of law, rights or ethics where you would welcome training and if yes, what are these?

Please use the box below to add any comments or observations you may have concerning the law, rights and ethics in the context of your experience of making difficult medical decisions for disabled children

Resources

62. How, if at all, does the availability of resources impact on your difficult medical decisions for disabled children?

63. What influence, if any, do you have on the allocation of resources for disabled children under your care?

64. What role, if any, does your hospital management play in these sorts of difficult medical decisions for disabled children?

65. Please use the box below to add any comments or observations you may have regarding resources in the context of your experience of difficult medical decision making for disabled children.

More information about you

This section asks for more information about you. The questions in this section are all optional, but it would be much appreciated if this information could be provided. The data collected in this section will **NOT** be attributed to individuals.

66. Have you ever lived outside of the UK for a period of more than 1 year?

No/Yes, I have lived abroad as a child below the age of five years old/Yes, I have lived abroad as a child between the ages of five and ten years old/Yes, I have lived abroad as a child over the age of 10 years old/Yes, I have lived abroad as an adult for between one and three years/Yes, I have lived abroad as an adult for more than three years/Yes, I completed part or all of my medical training abroad/Yes, I have worked as a qualified doctor outside of the UK

67. If you have answered yes to the last question, please name the country/ies where you have lived.

68. How would you describe your ethnic origin

English/Scottish/Welsh/Northern Irish/Irish/British/Gipsy
Traveller/Polish/European/Pakistani/Indian/Bangladeshi/Chinese/African/Caribbean/Arab/Mixed
or multiple ethnic origin/Other

If you selected Other, please specify:

69. How old are you?
Please select

Under 18 years/Between 18- 25 years/Between 26-34 years/Between 35-44
years/Between 45-54 years/Between 55-64 years/Between 65-74 year/75 years or over

70. Are you a parent?
Yes/No

71. If yes, what impact, if any, did becoming a parent have on your decision making in these types of circumstances?

72. Do you have any personal experience of living with disability?
No personal experience/I have a disability myself/I have experience of parenting a disabled child/I had a disabled sibling as a child/I have or have had a close relative (other than a son or daughter) with a disability/Other

If you selected Other, please specify:

73. If you have personal experience of living with disability, what impact, if any, do you think this experience has on your difficult medical decision making for disabled children?

74. Do you regard yourself as belonging to any particular religion or faith?

Please select

No/Christian-Protestant/Christian- Roman Catholic/Christian-Other/Buddist
Hindu/Jewish/Muslim/Sikh/Other

If you selected Other, please specify:

75. As a child, were you brought up in a particular religion or faith?

Please select

No/Christian-Protestant/Christian-Roman Catholic/Christian-Other/Buddist
Hindu/Jewish/Muslim/Sikh/Other

If you selected Other, please specify:

76. If you now have or were brought up as a child in a particular religion or faith, what impact, if any, do you think this has on your difficult decision making for disabled children?

77. What changes would you make to the way difficult medical decisions are made for disabled children in the UK?

78. Please use the box below to add any comments or observations you may have about your experience of making difficult medical decisions for disabled children or about this survey or research.

Thank you for your valuable time and for completing this survey.

Consent Notice

The data supplied by you for this survey will be used as part of PhD research examining difficult medical decision making for the UK's disabled children.

This survey has ethical approval from the University of Edinburgh and has been approved as not needing "NHS ethical review under the terms of the governance arrangements for research ethics committees in the UK" by the South East Scotland Research Ethics Service.

All raw data collected will be kept securely and accessed only by the researcher.

Your name and place of work will be kept confidential, although reference may be made in any published work arising from this survey to your job title and the NHS region in which you work.

Any personal information, such as religious beliefs, ethnic origin or personal experience of disability will not be attributed to any individual participant.

CLICKING ON THE **CONTINUE** BUTTON INDICATES YOUR CONSENT TO BE A PARTICIPANT IN THIS SURVEY.

Finish

Appendix 5

Letter to interviewees

Dear Dr X

Difficult Medical Decision Making for the UK's Disabled Children

Thank you for agreeing to meet with me/speak with me by telephone at

[]

to discuss your survey responses and difficult decision making for disabled children in more detail.

I shall [detail of arrangements for meeting or telephone conversation].

As you will recall the primary purpose of my PhD study is to ascertain how doctors make difficult medical decisions for disabled children in reality and what influences those decisions.

You will also recall for the purpose of this study the term "disabled children" is used to describe children with chronic health conditions and physical and sometimes sensory and cognitive impairments. These children will often have some level of neurological impairment, will often be described as having "life limiting" conditions, although they will not necessarily be terminally ill.

Your name and contact details will be kept confidential. Your participation in this research will be kept confidential and all original data will be stored securely and will only be accessible by me. Every attempt will be made not to identify you in my thesis or in any subsequent publications. Information you provide will not be published in such a way that you would be readily identifiable. However, due to the close nature of the paediatric profession there is the possibility that a colleague may be able to identify you from information provided.

With your consent our discussion will be recorded using a recording App on a mini iPad. I am happy to provide you with a copy of the transcript of our discussion once it has been transcribed.

This research has ethical approval from the University of Edinburgh and has been approved as not needing 'NHS ethical review under the terms of governance arrangements for research ethics committees in the UK' by the South East Scotland Research Ethics Service.

When we meet/speak, I will remind you of this information and also ask for your consent to make the digital audio recording.

You will be free to withdraw from this research at any time.

Thank you for being generous with your time.

I look forward to meeting/ speaking with you.

Kind regards

Appendix 6

Interview Plan

Questions and question areas to address.

There are three groups of questions

- (1) questions to all doctors;
- (2) questions tailored dependent on doctor's survey responses; and
- (3) questions about law, rights and ethics.

Doctors will be encouraged to reflect freely and 'dictate' largely the areas to be discussed, so all questions will only be used if necessary and as prompts.

Preliminaries

- Thanking them for their time
- Consent and confidentiality
- Outlining research

Questions to all doctors

I would like you now to reflect on how you make clinical decisions.

These are some of the areas I am interested to know more about:

1. What are types of difficult medical decisions you are called upon to make?
2. What differences are there, if any, in the way you approach these decisions if the child in questions is significantly disabled?
3. What resources do you draw on when making difficult decisions?
 - Prompts –
 - colleagues
 - medical/non-medical
 - child's family
 - the child
 - guidance
 - ethics committees
 - law/rights
4. What would make these kind of decisions easier
 - Prompts
 - Resources
 - More professional bodies could do eg RCPCH/GMC
 - Training /education
 - Colleagues
5. A study [give brief detail] reported in the Lancet found that doctors across Europe were greatly influenced by their faith when making clinical decisions, what is your experience in this regard?
6. Do you think there is any difference between the way male and female doctors approach difficult medical decisions?
7. Aaron and Schwartz American researchers who did a study in the 1980s in the UK, found that British doctors *"British physicians often appear to rationalize or at least redefine, medical standards so that he can deal more comfortably with resource constraints"*. They reported *"Thus it is clear that not all British doctors believe they are providing all potential beneficial care to their patients. Many realize, according to one consultant, that they are acting as society's agent in rationing care"*.
 - Does this chime with your experience?
 - How does it manifest itself in day to day practice.
 - What impact, if any do you think it has on the care of disabled children or children with more complex health needs?

Then go on to ask whether they have experienced disabled children not getting care, eg ITU; ventilation; antibiotics.

Questions specific to doctor's circumstances

1. Question on specialism – whether the doctor thinks doctors from different specialisms approach difficult decisions differently? If yes, how, why doctors think this is?
2. Question on different hospitals or different departments – whether there are work place cultures that developed and what influences this is it does happen, is it a “key player” ie influential senior doctor who sets tone of department or hospital.
3. Question to doctors who are parents as to whether and if so how being a parent changed their approach
4. Question to doctors who are parents of disabled child whether this changed their approach. Do they find their approach differs from other doctors.
5. Question to doctors who have worked abroad on difference seen, particularly with regard to care and treatment of children with significant disability.

Questions on law, rights and ethics

1. Taylor question to individual doctor about their own education and training in these areas, e.g. ask those who have had significant training and education, why and what difference if any it has made. Those who have not, why not and whether they think more training in law, rights and ethics would help.
2. Questions about relevance of law, rights and ethics to doctor's work and doctor's understanding of these disciplines in relation to their work.
3. How aware are doctors of case law?
 - e.g. are they aware of cases such as Glass/Wyatt/ or some of the less “high profile cases”?
 - How if at all do cases feed into their practice?
 - What is their perception of the courts approach? (may say they don't have one)
4. Question about use of professional guidance using RCPCH guidance on withdrawing and withholding care as example – exploring doctors' awareness and use of guidance? E.g.
 - Are they aware of it? (Only two mentioned it in survey)
 - How do they keep up to date with new guidance, what about junior colleagues?
 - Do doctors discuss it with colleagues either in theory or in practice in real life case situations?
 - What do they think of this kind of guidance?
5. Question about dealing with conflict disagreement, with colleagues and with families. How it is dealt with; whether there are better ways it could be addressed.
6. Question of any suggestions/ recommendations doctors have to improve care for disabled children from perspective of doctor, child & family.

END