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'Not fitting in': negotiating multiple illnesses and/ or disabilities

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PhD Thesis  
2015

# Abstract

The existing social sciences literature has placed considerable emphasis on the experiences of people living with singular illnesses or disabilities (Clarke and Griffin 2008). In this thesis it will be argued that it is also important to explore people's experiences of negotiating multiple illnesses and/ or disabilities. The number of people living with three or more long- term conditions in England is expected to rise from 1.9 million in 2008 to 2.9 million in 2018 (Department of Health 2012). Despite this significant increase, the voices of people negotiating multiple illnesses and/ or disabilities are rarely heard in academia, politics, activism, medicine, education, employment and civic society.

Using data generated during semi- structured interviews conducted in the North- East of England, this piece of research explores the extent to which people negotiating multiple illnesses and/ or disabilities present a challenge to dominant expectations about the functions, capacities and conduct of bodies across time and space. I will specifically examine the ways in which participants in this research do not 'fit into' three important settings/ contexts: (i) clinical encounters, (ii) spaces of mobility and (iii) imaginations of (hopeful) futures. Predominantly shaped by epistemological, methodological and empirical insights from existing feminist social sciences literature, this research focuses on the individual and collective (emotional, relational, material) implications of negotiating the (often) uncertain, confusing and incomprehensible bodily experiences associated with 'managing' multiple illnesses and/ or disabilities.

As well as providing a space in which the voices of this previously silenced group of people are heard, this thesis prompts consideration of the structures, processes and practices that shape and constrain people negotiating multiple illnesses and/ or disabilities. Addressing such problems necessarily involves destabilising accepted norms about how bodies 'should' operate in particular spaces, at particular times and, thus, presents a critique to dominant and standardised ideas about how our society 'should' be organised. One important consequence of the contravention of such societal expectations by people negotiating multiple illnesses and/ or disabilities is the sense that multiply ill and/ or disabled bodies are less valuable than other bodies: an idea that this research seeks to challenge. In doing so, this thesis not only contributes to the development of the existing social sciences literature that currently focuses on experiences of people with singular illnesses and/ or disabilities, but also provides discussion that medics, activists and policy makers (amongst others) may find interesting.

## Declaration

The material contained in this thesis has not previously been submitted for a degree in this or any other institution. It is the sole work of the author.

## Statement of copyright

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# Acknowledgements

Throughout the process of conducting this PhD research I have been helped by many individuals, communities and institutions. I would like to briefly mention these contributions to this work and to express my gratitude to those who have supported me on both an academic and personal level over the past few years.

Firstly, I would like to express my sincere thanks to everyone who participated in this research. The data presented in this thesis was generated because people kindly invested their time and energy in speaking to me about their lives. This process of data generation involved discussing sensitive issues which, I appreciate, presented significant difficulties for some participants at some times.

I am also extremely grateful to everyone at the Waddington Street Centre (WSC- the research site where most participants were recruited from) in Durham, North- East England, who made me feel very welcome over the past few years. I had the opportunity to attend the WSC on a weekly basis over a period of several years- something which I looked forward to every Thursday. This research has been supported by the board of the WSC as well as service- users, volunteers and staff. I would like to particularly mention the support of Andrew, Craig, Fergus, Gemma, Gill, Joan, Paul, Paula, Peter, Ruth, Steve, Susan and Val. Additionally, Ali Lee (the deputy manager of the WSC) has provided me with a lot of help over the course of the research, both practically and emotionally. Without Ali Lee, conducting this research would have been a much more difficult process- her enthusiasm, kindness and good humour has helped sustain me over the last few years.

I would also like to thank my PhD supervisors: Prof Sarah Atkinson and Prof Sarah Curtis for their advice and support over the years. Sarah A has provided me with the opportunity to discuss my ideas in detail, as well as guiding me through difficult periods. Her creativity, patience and positivity has been of great help to me over the course of this PhD. Sarah C mainly contributed to the early stages this research's development, at which time she was very encouraging and supportive towards me and this project.

The broader geography community at Durham University has also been a source of significant advice and support over the course of the PhD. The Geographies of Health and Wellbeing (GoHWell) research group has provided a space to exchange ideas and to get to know people interested in similar topics. The postgraduate and staff communities have also been of great help to me. From the department I would like to particularly mention the advice



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and support of: Alice, Ankit, Bishnu, Boris, Cheryl, Emma, Gordon, Janet, Jayne, Jenny, Lizzie, Marisa, Martin, Matt, Pammi, Peter, Philip, Rachel, Rob, Ruth, Simon and Veronica.

Further, I would also like to acknowledge the financial support provided to me by the ESRC (Economic and Social Research Council) and, latterly, the NEDTC (North- East Doctoral Training Centre). Without this assistance, I would not have been able to undertake this research. I am very grateful that this funding was available to me.

I would also like to thank my family and friends for supporting me over the course of this research, particularly during times of difficulty. As always, my Mum (Valerie) and Dad (Edward) supported me at every stage of the process- providing me with listening ears, motivation, perspective and lots of humour. My brother (Steven) was also a great source of support, both emotionally and practically. I'd further like to mention the support of friends who were there to help me, including: Abi, Christine, Kirsten, Laura, Lucy, Rosie and Vicky.

## Chapter 1: Introduction

### 1.1 'Not fitting in': multiple illness and/ or disability experiences

*"...which behaviours do you class as belonging to a particular labelled illness or disorder or condition?"* (Stephanie)

This rhetorical question, posed by a participant in this research, is at the heart of the problem facing many people negotiating *multiple* illnesses and/ or disabilities: how can symptoms be untangled and isolated within the body? Why is it necessary to separate out particular forms of bodily difference and who does this benefit? And, what happens when particular bodily experiences and capacities cannot be defined, understood or categorised? These are some of the questions that this research addresses, with the aim of understanding the processes that shape people's experiences of negotiating multiple illnesses and/ or disabilities.

The qualitative social sciences has placed emphasis on understanding the lived experiences of those with singular conditions (Clarke and Griffin 2008), but it is also important to consider the experiences of those negotiating multiple illnesses and/ or disabilities. As shall be explored in this thesis, living with multiple illnesses and/ or disabilities cannot be straight- forwardly perceived as additive in nature. Instead, there are complex entanglements at play that are often difficult to understand and respond to. Thinking about the fluidity of space, time, identities and bodies- with emphasis on commonalities and differences characterising people's experiences- enables unpacking of some of these difficult issues.

It is especially timely to consider this issue because of the huge increase in the number of people living with multiple illnesses and/ or disabilities. The Department of Health (2012) estimates that one million more people in England will be living with three or more long- term conditions in 2018 than in 2008 (approximately a 50% increase over the decade). Despite this increase, the voices of those negotiating multiple illnesses and/ or disabilities are rarely heard within academia, politics, activism, education, employment and civic society. In my opinion, disclosing diagnoses of 'too many' illnesses and disabilities is often met with a sense of incredulity, scepticism, frustration or even ridicule. This is a problem that needs to be explored within the social sciences- not only because of the devastation and isolation that such voicelessness often causes, but also because of what these experiences can tell us

about our understandings of bodies, medicine, mobilities and narratives of futures (amongst many other topics).

My motivation to write about this issue comes after conducting interviews with people who experience mental health problems. At the start of this research I was focused on listening to these people's experiences and trying to understand more about their lives. After speaking with a few people who attend a mental health resource centre in Durham (called 'The Waddington Street Centre'), I realised that people tended to discuss their experiences of multiple (rather than singular) illnesses and disabilities. By reflecting on this point, I became aware of the considerable opportunities associated with focusing my project on people's experiences of negotiating multiple illnesses and/ or disabilities.

Although the voices of this group of people have rarely been heard within the social sciences, there has been research conducted that encourages consideration of the different ways in which particular types of illnesses and disabilities impact on people's lives. For example, Wendell (2001) explains this idea with reference to the different experiences of the 'healthy disabled' and 'unhealthy disabled':

"... there are important differences between healthy disabled and unhealthy disabled people that are likely to affect such issues as treatment of impairment in disability and feminist politics, accommodations of disability, activism and employment, identification of persons as disabled, disability pride, and prevention and "cure" of disabilities." (Wendell, 2001: 17)

Consideration of the different ways in which illnesses and disabilities are perceived is, clearly, very important for several reasons. But, how do people who may be considered as both 'healthy disabled' and 'unhealthy disabled' (Wendell 2001) negotiate issues of identity, activism and access to resources (amongst many other issues)? This is a question that has yet to be addressed within the social sciences, making the work of this thesis important and timely.

## 1.2 Research aims

The aims of this research have changed significantly over time. In *Chapter 3* of this thesis, I explore the nature and implications of some of these changes as part of an effort to destabilise notions of linearity and simplicity in the research process. Whilst acknowledging this complexity, at this stage it is useful to explore the 'final' aims of this project as they align to the work of this thesis. These aims are also intended to meet the specific requirements

and expectations of submitting a geography thesis at Durham University, United Kingdom. Furthermore, as only one output of my research, the aims of this piece of work are a reflection of specific aspects of this topic that are of particular academic importance and interest to me (and, hopefully, to others).

There are three interconnected aims that will be addressed in this thesis, as follows:

- a) to explore and account for the ways in which negotiations of multiple illness and/ or disability experiences are felt, lived and responded to in various contexts (such as in clinical settings and imaginations of futures);
- b) to examine some of the (emotional, social, economic, material, relational) implications of negotiating the (often) uncertain, confusing and incomprehensible bodily experiences associated with living with multiple illnesses and/ or disabilities;
- c) to set out some of the problems and challenges that such multiply ill and disabled bodies present for the way our society currently operates (for example, in relation to expectations of bodies in workplaces and the organisation of public transport infrastructure).

The case for setting the first aim is explained in significant detail in *Chapter 2*. Specifically, through a review of the existing social sciences and disability studies literature, it is demonstrated that there has been a neglect of the voices of people negotiating multiple illnesses and/ or disabilities. With this academic gap in mind, it is important to begin to explore this issue in detail, especially in relation to the different manifestations of people's multiply ill and disabled bodies in different contexts. These spatial and temporal considerations shape and frame people's bodily experiences and are, thus, a key aspect to exploring the lives of participants in this research. Throughout this thesis, the heterogeneity of people's experiences will be emphasised alongside the idea that there are common themes across such experiences.

Secondly, the work of this thesis will seek to extrapolate the multi- various ways in which participants' bodies are (often) characterised by uncertainty, confusion and incomprehensibility. The *multiplicity* of symptoms is argued to present particular difficulties to the lives of participants. It is often impossible to isolate one symptom from another, resulting in significant barriers to understanding and responding to multiple, difficult bodily experiences. This poses particular challenges to diagnosis and treatment, as well as in explaining bodily behaviours to others. As shall be explored, there is a moral dimension to living with such uncertain, confusing and incomprehensible bodily experiences- with participants often experiencing stigma, isolation and even ridicule because they are living with 'too many' problems. The 'legitimacy' of such multiple ill and disabled bodies is called

into question in many contexts, especially given the dominance of notions of rationality, stability and progress in our society.

Building on this idea, the third aim of this thesis is to explore the challenges that the bodies of people negotiating multiple illnesses and/ or disabilities present to our society. Significant attention is placed on the ways in which existing structures and attitudes impact on the lives of participants in this research. For example, in *Chapter 4* I explore the price which many people living with multiple illnesses and/ or disabilities pay for having bodies that are not viewed as rational and stable. Such bodies are routinely devalued and met with resistance. The idea that the bodies of participants in this research are viewed as a 'problem' is discussed throughout this research, before being focused on in detail in the concluding chapter of this thesis.

### 1.3 Key concepts

Before addressing these aims, it is important to briefly define the key concepts that inform the work of this thesis. Specifically, at this point, I would like to explain how I understand and make use of the three terms that form the title of my research<sup>1</sup>.

#### a) 'Not fitting in'

The idea of 'not fitting in' is mentioned in several research participants' accounts of negotiating multiple illnesses and/ or disabilities. As will be discussed in the empirical chapters presented in this thesis, notions of 'fitting in' and 'not fitting in' are explored and critiqued in relation to specific contexts (including clinical settings and narratives of futures). The degree to which research participants 'fit into' specific settings is highly variable and, thus, tells us about the way particular spaces are imagined, organised and experienced. For example, in *Chapter 5* I argue that the clinical spaces of diagnosis and treatment are sometimes exclusionary to people negotiating multiple illnesses and/ or disabilities. The organisation and practice of diagnosis and treatment often curtails discussion of multiple illnesses and/ or disabilities in favour of focusing on singular diagnoses. In each clinical encounter it is shown that there is little opportunity for patients to discuss unexplained and contested aspects of their multiply ill and/ or disabled bodies in the context of clinicians endeavouring to isolate specific aspects of bodily difference from one another. Hence, in

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<sup>1</sup> Elsewhere in the thesis, I pay considerable attention to the additional ideas that inform this research. For example, in chapter 3 I explore how feminist epistemologies have shaped my approach to my work.

settings such as these (amongst others) the experiences of participants in this research challenge many of our society's expected and accepted attitudes about the conduct of bodies.

b) Negotiations

Throughout this thesis I refer to participants' 'negotiations' of multiple illnesses and/ or disabilities. Use of this word is firstly reflective of the ongoing nature of people's illness and disability experiences. This word choice also communicates the multiple issues that participants have to constantly weigh up. The priorities of individual participants in this research are variable- as a consequence of changes in spaces, bodies and emotions. This point is evident in relation to the work of *Chapter 6* in which it is demonstrated that participants' mobility experiences are often shaped by competing illness and disability considerations. Mark, for instance, explained to me during our interview that he makes decisions about his ability to travel by bus based on his (variable) anxiety, pain and irritable bowel syndrome symptoms- alongside considerations about the frequency in which buses are scheduled and the time a journey will take.

c) Multiple illnesses and/ or disabilities

The choice about whether to refer to participants in this research as 'ill' or 'disabled' is a difficult one. Throughout this thesis I refer to participants in this research as negotiating 'multiple illnesses and/ or disabilities'. Whilst acknowledging the problems associated with deploying this term, in the context of this research, it is appropriate to refer to participants as negotiating multiple illnesses and/ or disabilities. At this point in the thesis, I would like to discuss my rationale for the development of this phrasing- as well as exploring some of the advantages and disadvantages of its use.

Firstly, it should be noted that none of the participants in this research refer to themselves as negotiating multiple illnesses and/ or disabilities. Instead, people made use of a variety of different terms to describe their forms of bodily differences, including (but not limited to): i) 'being ill', ii) 'being disabled', (iii) 'living with anxiety', iv) 'being a lonely person', v) 'being weird', vi) 'having pain', vii) 'collecting conditions' and viii) 'having many problems'. Participants also tended to use different terms in different ways at different points during the interview process. My decision to refer to this group of people as negotiating multiple illnesses and/ or disabilities is not intended to override or devalue participants' voices, rather it is a practical move that aims to emphasise both the individual and collective aspects of people's experiences.

In addition to this issue, choosing whether to refer to forms of bodily difference as *either* illnesses or disabilities is fraught with difficulty. Each word has different histories, meanings and usages. These differences are discussed in significant detail in the next chapter, which explores the academic and societal gaps between understandings of illnesses and understandings of disabilities. Although there are differences in the ways these terms are understood, there also seems to be a degree of overlap between them. By making use of both words throughout this thesis, I seek to emphasise that although there were differences and variabilities in how participants narrated their illness and/ or disability identities, there were also similarities. The implications of narrating experiences in terms of either illness or disability are explored in the next chapter in relation to illness and disability politics, negotiations of identities and access to resources.

In some social sciences and health literature the author provides definitions of key terms (such as 'illness' or 'disability') used in the research. In the case of this particular topic, World Health Organisation (WHO) or Department of Health (England and Wales) criteria may be referred to. But the (re) production of such parameters around who 'counts' as ill and/ or disabled is a highly problematic process that will inevitably exclude people who (i) have not received diagnoses, (ii) contest clinicians' diagnoses, or (iii) cannot access medical services (amongst other groups of people). Instead, the approach of this research is to concentrate on the meanings, politics and understandings that participants have of their own bodies and lives. This is a particularly important issue for this project because several of the participants in this research do not 'fit into' some of the existing biomedical and social categorisations of 'illness' and 'disability'.

For the purposes of this research I have also phrased people's experiences of two or more illness and/ or disability identities in terms of negotiating *multiple* illnesses and/ or disabilities. Some researchers may have chosen to write about people's experiences of 'comorbidity', rather than 'multiple' illnesses and/ or disabilities. Although the deployment of this word may have resulted in a more lucid writing style in this thesis, discussion of 'comorbidity' has highly medicalised connotations. Instead, referring to the negotiation of multiple illnesses and or/ disabilities is more suited to discussion of the political and social dimensions of people's experiences.

Additionally, I would like to acknowledge that the process of making a distinction between singular and multiple illnesses and/ or disabilities can be problematic in some instances. For example, some participants reported that their multiple illnesses and/ or disabilities could sometimes 'merge together'. This research does not take an additive approach to people's multiple illness and/ or disability experiences. Instead of counting the number of illnesses

and/ or disabilities that people have, my focus is on the complexities, contradictions and ambiguities associated with negotiating multiple illness and/ or disability identities.

## 1.4 Methodology introduction

To address the aims of this work, I designed a qualitative research project that generated data about the lives of people negotiating multiple illnesses and/ or disabilities. The majority of participants in this research were recruited from a mental health resource centre in the North- East of England, called 'The Waddington Street Centre'<sup>2</sup>. People attending this centre come from the local area and are typically referred there by a community psychiatric nurse (CPN), social worker or other health and social care professional. Discussed in more detail in *Chapter 3* of this thesis, the centre provides life skills and opportunities aimed at either maintaining or improving a person's mental health. This includes offering courses (such as art, poetry, music, cooking and sports), as well as providing emotional support. In addition to recruiting service- users to participate in this research, I also interviewed several staff members whose perspectives are quoted at various points throughout this thesis. Some of the other participants in this research were recruited through a snowball sampling technique. These people did not attend the Waddington Street centre, but agreed to participate in the research in order to tell me about their illness and/ or disability experiences.

People who identified as negotiating anxieties (such as obsessive compulsive disorder (OCD), panic disorders and post- traumatic stress disorder (PTSD)) were asked to participate in a one- to- one interview with me. During all of these interviews, participants mentioned that they were negotiating multiple illnesses and/ or disabilities. Although my starting point for recruiting participants was through the lens of 'anxieties', the research developed to consider people's multiple illnesses and/ or disability experiences. Discussing this sensitive research topic with participants obviously entailed negotiating a number of ethical issues, which are discussed in *Chapter 3* of this thesis. This thesis focuses on data generated during these semi- structured interviews to explore the many and various issues experienced by people negotiating multiple illnesses and/ or disabilities, whilst remaining mindful and respectful of the personal nature of participants' experiences.

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<sup>2</sup> It was a condition of conducting this research that the name of the centre should be used in any published outputs. Discussion about the rationale and ethics of this is discussed in much more detail in Chapter 3.



## 1.5 Scope of the project

This thesis is offered within the context of some tight practical boundaries. Firstly, although this research is shaped by extensive engagement with existing (particularly feminist) health and disability literature within the broader social sciences, my primary focus is on the experiences of research participants. In that sense, I place considerable emphasis on reflecting the complexities and ambiguities associated with negotiating multiple illnesses and/ or disabilities. As far as I am aware, this is a task that has not been undertaken elsewhere. Although this is the stated focus of this project, my intention is not to diminish the value of either more philosophical or more applied work. Rather, my particular approach to this topic is shaped by the same time constraints that face every researcher: it is never possible to consider every important and interesting angle of an issue.

I also think this approach is best matched with my academic background and skills. Although a geographic approach is evident throughout this thesis, I have not been limited to this body of literature. I have engaged with research and ideas from disability studies, sociology and the broader social sciences. Rather than territorially focusing on the human geography literature (given that this is the academic tradition I am familiar with), there are considerable benefits of reading beyond disciplinary boundaries- as I hope is demonstrated throughout this thesis.

Further, this research should be understood as just one contribution to the exploration of the issue of people's multiple illness and/ or disability experiences. This work does not aim to be representative of people's experiences in order to reach reliable conclusions about everyone who lives with multiple illnesses and/ or disabilities. Rather, my partial perspective is emphasised throughout this research- in relation to my reading of the literature, ideas that are discussed and analysis of participants' perspectives. This approach to addressing this topic is a particularly important aspect of challenging the problematic epistemological, methodological and empirical legacies of social sciences disciplines that have routinely sought to claim 'expert' status over the lives of groups of people that they have often contributed towards the silencing of (such as women, people with disabilities, people of colour and others)<sup>3</sup>.

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<sup>3</sup> This issue is discussed in much more detail in chapters 2 and 3 of this thesis.

## 1.6 Structure of the thesis

This thesis is comprised of eight interlinked chapters (including the introduction and conclusion). In seeking to address the three research aims posed in this work, each chapter is dedicated to exploring a particular theme that contributes to the overall direction of the thesis. Alongside the literature- based and methodological chapters, four empirical chapters are presented. Each of these empirical chapters has the aim of exploring a particular idea, setting or context that featured prominently in participants' accounts of their lives. In some ways, this thesis may be perceived as following a conventional structure because of the use of such a linear layout. Although there are some differences between my thesis layout and that of a conventional geography thesis (such as my inclusion of pieces of ethnographic fiction- explained in *Chapter 3*), this fairly conventional structure is well suited to addressing the issues that I would like to discuss. For example, some researchers may not include a literature review chapter at the beginning of the thesis, in favour of integrating empirical analysis with ideas from the existing literature throughout the whole thesis. Although I do integrate such ideas together throughout the remainder of the thesis, I have chosen to write a literature review chapter in order to establish the foundation on which the thesis is based. Along with discussing the rationale for including a literature review, I will now briefly explain the topics discussed in each of the subsequent thesis chapters.

The role of the literature review (*Chapter 2*) is to identify, explain and challenge the 'gap' between understandings of illness and understandings of disability. It will be shown that the terms 'illness' and 'disability' have quite different academic and societal meanings. The specific academic histories of those focusing on disability and those focusing on chronic illness have given rise to the (re) production of division based on forms of bodily difference. This has implications for access to resources and identity negotiations, to name just two issues. Although in this chapter I seek to understand and explain why people's forms of bodily difference have been divided up in such ways, I also argue that these traditions need to be challenged. Academic and societal tendencies to imagine those living with illnesses in quite different ways to those living with disabilities have left no space for the voices of those living with both illnesses and disabilities. It is within this context that the importance of listening to the previously unheard voices of those negotiating multiple illnesses and/ or disabilities becomes clear.

After exploring this gap, in *Chapter 3* I set out my approach to the conduct of research about this topic. In this chapter I begin by exploring the feminist epistemological position that has informed this research project. Although this thesis is intended to be focused on the experiences of participants in this research (rather than solely on conceptual issues), it is valuable to explore the particular modes of thinking and doing that have shaped my approach to this issue. It is in this context that presenting a discussion of key feminist concepts can help to communicate the approach that this research takes. Informed by this feminist approach, the remainder of the chapter is dedicated to discussing research aims, sites, recruitment, conduct of interviews, ethics, and approach to analysis and writing. The role of this chapter is therefore to explain and justify my research approach, whilst reflecting on the parameters and limitations of this project.

In this first empirical chapter of the thesis, *Chapter 4* is focused on the bodily experiences of participants in this research. Although this focus on bodies is a key theme throughout this research, the aim of *Chapter 4* is to analyse the ways in which multiply ill and/ or disabled bodies come to be understood (or fail to be understood) in the context of the privileging of particular bodily behaviours and capacities. Specifically, I argue that ambiguity, variability and unpredictability are often key aspects of participants' accounts of negotiating multiple illnesses and/ or disabilities but that these experiences are devalued in our society. In the first part of the chapter I explain that dominant conceptions of bodies as rational, bounded and productive have led to the relegation of bodies that undermine these norms. Given this situation, participants in this research narrated 'alternative' understandings of their bodies- as discussed in the final section of the chapter. Hence, the role of this chapter in the thesis is to integrate conceptual and empirical insights to explore the sense of incomprehensibility (lack of understanding, clarity and predictability) that characterises many participants' experiences of multiple illnesses and/ or disabilities, as well as underscoring the implications of living with such incomprehensibility.

After achieving this task, in *Chapter 5* I discuss one setting in which such 'incomprehensible' bodies frequently do not 'fit into': spaces of diagnosis and treatment. Despite the reasonable expectation that people living with multiple illnesses and/ or disabilities will feel accommodated in clinical settings, participants in this research routinely felt poorly understood and voiceless during clinical encounters. Clinicians' focus on the task of isolating particular diagnoses from other diagnoses leads to some people living with multiple illnesses and/ or disabilities feeling neglected during diagnosis and treatment. The tendency to seek to divide up bodily experiences in order to achieve singular diagnoses leaves 'no room' for the complexities and ambiguities that characterise people's experiences of multiple illnesses and/ or disabilities. The emotional consequences of this silencing are

significant for patients and- I argue in this chapter- prompt a rethink of the ways in which diagnosis and treatment are organised and practiced.

As well as this thesis' discussion of clinical spaces, I also focus on participants experiences of mobility in *Chapter 6*. Situated in relation to recent literature on the topic, this chapter considers the complexity of movement experiences (Andrews *et al.* 2012), rather than assuming that people straight- forwardly move between points on a map. It is argued that the mobilities of participants in this research are frequently at odds with the ways that bodies are expected to move. Sometimes these movements are considered unacceptable at particular times and in particular spaces- meaning that people also have to negotiate the emotional as well as practical implications of moving in ways that are different from the norm.

Another important aspect of the accounts that participants provided of their lives is in relation to their imaginations of futures (discussed in *Chapter 7*). In the same way that people negotiating multiple illnesses and/ or disabilities challenge the accepted organisation and practice of diagnosis, treatment and mobilities; participants in this research do not 'fit into' dominant conceptions of the future as both happy and hopeful. Strongly critiquing ideas from 'positive psychology' about the need to be happy and hopeful, I explore the ways in which past and present life experiences (including financial and health experiences) shape particular imaginations of futures. In a society that frequently devalues people's experiences of illnesses and disabilities (as discussed in the previous chapters), such 'pessimistic' narratives are a key feature of participants' imaginations of futures.

In the final chapter of this thesis (*Chapter 8*), I seek to bring together the ideas explored in the previous chapters in order to discuss the key findings and implications of this research. In this fairly extensive concluding chapter, I have orientated discussion around the concept of 'problems'. Specifically it is argued that this project has highlighted several problems that people negotiating multiple illnesses and/ or disabilities face. Although it is not the purpose of this thesis to make recommendations, I do raise some issues that I hope the reader will find interesting and important.

## Chapter 2: Literature Review

### 2.1 Introduction

Over the past 20 years, academic attention has been placed on the conceptual, empirical and political divides apparent between the social sciences and disability studies (Barnes and Mercer, 1996). Whilst those thought of as working within the social sciences have tended to focus on communicable and non-communicable illnesses, disability studies researchers have concentrated on the experiences of those described as disabled (Barnes and Mercer, 1996). But, as this chapter shall demonstrate, academia's (re)production of such a distinction between 'illness' and 'disability' is highly problematic. Dividing up bodies on the basis of a rigid dichotomy between the 'healthy disabled' (typically the domain of disability studies) and the 'unhealthy disabled' (typically focused on within the broader social sciences, although this group is more commonly referred to as experiencing 'illness' (Wendell, 2001)) has important implications for participants in this PhD research.

One key consequence of this division, and one which shall be explored in this chapter, is that a focus on the experiences of people who live with *multiple* illnesses and/ or disabilities has been largely absent from both the social sciences and disability studies literature. Quite simply, bodies which do not 'fit into' categorisations as straight-forwardly *either* ill *or* disabled (that is, not both) have been neglected within academia. Instead, particular illnesses and disabilities are routinely isolated within bodies, to the exclusion of broader bodily experiences, variabilities and capacities. Explaining the reasons for this silence within academia forms the key task of this chapter and will, in turn, set-out the academic context within which the work of this thesis becomes significant.

This task will be achieved in this chapter by addressing three inter-linked aims, as follows:

- a) To **identify** the ways in which the gap between understandings of 'illness' and 'disability' is evident within both society and academia;
- b) To **explain** the implications that this gap has for people living with multiple illnesses and/ or disabilities;
- c) To **challenge** the gap by (i) setting out some of the key ideas that cut across both the social sciences and disability studies literatures and, (ii) exploring how these ideas have shaped the approach taken to this research.

The first of these two aims will be the focus of the next two sections in this chapter whilst the final section will concentrate on the third aim. Addressing these aims will also help to form a picture of both the broader social sciences and disability studies literature<sup>4</sup>, as well as underscoring some of the problems associated with dividing up bodily experiences according to traditional, disciplinary conceptions of what 'illness' is and what 'disability' is.

## 2.2 The societal gap between understandings of illness and disability

The tasks of a) identifying the differences between understandings of illness and disability and b) explaining some of the implications this gap has for people negotiating multiple illnesses and/ or disabilities (corresponding to the first two aims of this chapter) will be tackled concurrently in both this section and the next section. Firstly, this section will explore the ways in which *wider societal understandings*<sup>5</sup> about the differences between illness and disability have shaped the ways in which this topic is understood. In section 2.3, I will go on to set-out reasons for the *academic gap* between research on illness and research on disability.

In terms of wider societal understandings about the differences between illness and disability, it is important to consider how people have come to view the terms in such different ways. Specifically, I will argue that the issues of *visibility* and *time* shape how we understand particular bodily differences as corresponding to categorisations of *either* illness or disability. By focusing on these two issues, an insight into societal understandings of illness and disability will be generated but this discussion is certainly not exhaustive. There are many lenses through which it is possible to chart society's perceptions of the differences between understandings of illness and disability but, within the word limit of this chapter, I only have scope to discuss the issues of visibility and time.

Those working within both disability studies and the broader social sciences have often accepted traditional, dominant and unspoken societal conceptions about the perceived

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<sup>4</sup> At this point it is important to explain that my intention is not to suggest that people working within disability studies are not 'social scientists' (or vice versa). Rather, this is a distinction that has been made in some of the literature (e.g. Barnes and Mercer 1996). In this thesis when I refer to the gap between disability studies and the social sciences, this is usually done with reference to particular academic ideas rather than particular academics' identities.

<sup>5</sup> This is a tricky term because of the heterogeneity of societies. In this section I refer to 'wider societal understandings' specifically in relation to ideas that are thought to be dominant, as identified in the academic literature.

differences between chronic illness and disability. Specifically, I firstly argue, these conceptions have their foundations in what Thomson (1997) describes as an “economy of visual difference” (Thomson, 1997: 8). Within this context, bodies that are perceived to be substandard become “spectacles of otherness” (Thomson, 1997: 8), in stark contrast to an able-bodied norm (Thomson, 1997). Wendell’s (2001) account of the distinction made between healthy and unhealthy disabled people is heavily aligned with the distinction made between those that are *visibly* disabled and those that ‘pass as normal’ (Thomson, 1997).

With this economy at work, those people with invisible chronic illnesses are often not viewed as disabled. For example, given that pain is an “invisible geography” (Scarry 1985: 3) that can be neither confirmed nor denied by others (Scarry, 1985), ‘coming out’ as having such an invisible identity often goes hand-in-hand with other people’s uncertainty about the credibility of claims (Samuels, 2003). Necessarily, this invisibility and individualising nature of pain prompts isolation from the wider world (Leder, 1990). Those with (visible) disabilities may also experience pain and isolation, but this could be met with different understandings and responses across time and space because their bodily differences can be seen by others.

Of course, what is visible or invisible to the world is bound up with issues of power. Haraway (1988) emphasises that those with ‘unmarked’ bodies (e.g. white, male bodies) inscribe power on ‘marked’ bodies (e.g. black, female bodies). This process of inscription is one which relies on the play between what is visible and what is invisible. Indeed, the accepted and ideal representatives of humankind are those which are not marked out by their bodies, but are rather invisible in a sense (Puwar, 2004). Despite the dominant view that everyone is able to occupy particular spaces and positions, there are those that are implicitly viewed as ‘natural’ occupants (for example, white men are often associated with powerful positions in workplaces) (Puwar, 2004). Evidently, an invisible ‘normality’ seems to be heavily associated with the exercise of power.

Although Puwar (2004) focuses her attention on race and gender, it is helpful to reflect on the implications of the marking practices she describes in relation to understanding the experiences of those with invisible disabilities. Initially, it seems as though the experiences of those with invisible disabilities do not neatly fit into the distinction made by Puwar (2004) between powerful marked bodies and less powerful unmarked bodies. Instead, people with invisible disabilities are much more difficult to categorise because they concurrently possess features typically associated with both disabled and non-disabled people (Lingsom, 2008). Specifically, they often ‘pass’ as ‘normal’ (not disabled), yet their bodies differ to the norm (Thomson, 1997). Hence, it seems that distinctions between societal understandings of

illness and disability are (at least partially) based on problematic distinctions about the visibility of bodily differences.

The difficulty associated with negotiating such invisible disabilities often lies in the process of managing perceived risks. According to Thomson (1997), people who may 'pass as normal' have to constantly weigh up the advantages and disadvantages of 'coming out' as disabled. The disbelief, based on the invisibility of an illness or disability (Lingsom, 2008), of various gatekeepers often hinders access to the help and resources needed by people (Davis, 2005). Having to 'come out' to people who question your credibility means that people with invisible bodily differences have experienced ridicule, embarrassment and condemnation (Davis, 2005). Hence, managing the risk of 'coming out' highlights that people's experience of (normally) invisible chronic illnesses may be different to those with often visible disabilities.

However, it is important to note this theorisation of 'passing' is also subject to debate. There may be two things at work regarding passing - passing deliberately and passing by default (Samuels, 2003). Indeed, as Samuels (2003) notes, she does not make a deliberate decision to appear as nondisabled (and heterosexual) when she leaves the house in the morning. This complicates matters and destabilises the idea that it could be a conscious choice about whether to 'pass' or not. Although important, I think Samuels' suggestion reinforces the point that there is a privileged norm that is in place, regardless of whether one makes the conscious choice to perform as that, or not. Clearly distinctions are made between usually visible disabilities and usually invisible chronic illnesses and- as demonstrated- this does have important implications for accessing resources, alongside other effects that will be discussed in this thesis.

Deeper reflection on the debate about 'passing' undermines the persistence within an "economy of visual difference" (Thomson, 1997: 8) of what is already a precarious distinction between visible disabilities and invisible chronic illnesses. Whilst there has been a lot of discussion in the literature about the implications of experiencing *either* visible *or* invisible illnesses and/ or disabilities, there has been little focus on those illnesses and/ or disabilities which may be visible at certain times but invisible at other times (Smith, 2012). For example, epilepsy may be invisible to others for most of the time but then suddenly become visible if the person living with epilepsy has a seizure (Smith, 2012). In such situations, the unpredictability of bodies means that space is experienced as fluid and uncertain (Smith, 2012), rather than an inconsequential, homogeneous background to people's experiences of illnesses and/ or disabilities.



Additionally, this importance of space specifically in relation to the issue of visibility/invisibility is inseparable from the politics of what is made visible or invisible (where this choice exists). Instead of appearing uniform across time and space, Zitzelsberger's (2005) research noted that all of her participants have used strategies to hide their disabilities, including avoiding particular social settings and covering up parts of their bodies. Furthermore, in a study by Crooks *et al.* (2008), women living with fibromyalgia syndrome in Ontario, Canada, who did not normally identify as disabled, undertook "strategic performances of the self" in health care and social security settings (Crooks *et al.* 2008: 185). When in these sites of state control in which access to material resources was at stake, adopting a disabled identity was crucial (Crooks *et al.* 2008). In the context of the state determining access to support as dependent on appropriating a 'disabled' identity, we can see that emphasising aspects of a non-disabled identity may have negative consequences for the individual. This variation over space highlights the changeability and multiplicity of ways in which disabled identities are experienced (Zitzelsberger 2005). Managing such a 'revolving door' in which people are constantly assessing whether disclosure is possible or desirable is by no means easy and can be made even more complicated if people experience conditions (such as autism) which reduce the ability to weigh up the safety of 'coming out' (Davidson and Henderson, 2010).

In the first part of this section, an exploration of the literature has supported the argument that issues of visibility are an important method through which society understands the distinction between chronic illnesses and disabilities. But this distinction has also been problematized not only because what is 'visible' may change over time and space, but also because of the consequent moral hierarchizing of particular bodily differences that is propagated. As shall be demonstrated in this thesis, the complexities associated with living with both visible and invisible illnesses and disabilities also mean that individual and collective identities do not neatly 'fit into' such categorisations of bodily differences.

Issues of temporality account for a second way in which society perceives distinctions in understandings of illnesses and disabilities. It is argued that the distinction between the two terms relies on a particular theorisation of how particular bodily experiences of illness and disability relate to particular temporalities. Whereas disability is typically understood to be a permanent and unchanging bodily experience, chronic illness is thought of as much more variable. This idea is explained with reference to an example of how experiences of work are shaped by dominant societal ideas about the differences between chronic illness and disability.

Living with a (permanent) disability is perceived as oppositional to working in some employment sectors. There is a sense that the bodies of people with particular disabilities will *never* be consistent with the demands of some workplaces. This is particularly apparent if we think of the routinized labour temporalities expected within factory environments. For instance, in Gleeson's (1999) research about disability in colonial Melbourne, he shows that issues of expected *pace* were instrumental to the functioning of a 19<sup>th</sup> Century Biscuit Factory. One record from the 4<sup>th</sup> of June 1889 at Guest's Biscuit Factory notes that a 15 year- old boy was dismissed because his paralysed hand did not make him a good worker. Being a 'slow' factory worker was viewed as a permanent feature of this 15 year- old's body- having a paralysed hand was never going to be consistent with this form of factory work. This example highlights a number of issues in relation to the experiences of people with disabilities in workplaces, including the importance of the relationality of other 'normal' bodies in demarcating 'slower' bodies as disabled. In the context of an economic system in which profits are maintained and increased by working at a particular place, bodies that 'fail' to meet this expectation are viewed as disabled. Significantly, within this economic and social environment, it is this permanence of bodily difference that is perceived of as disabling.

However, understandings about chronic illnesses (despite being 'ongoing') are typically viewed as much more variable than (unchanging) disabilities. As Wendell (1996) outlines in relation to her own experience of living with M.E., her variability in bodily experiences and capacities is difficult to predict and manage. At odds with common perceptions about the stability of 'disability', living with M.E. means facing several uncertainties that also intersect with other identity negotiations (Wendell 1996) (for example, in relation to age and gender categorisations). This point is explained in Wendell's account of being a young person with a chronic illness:

"... inhabit[ing] a category not easily understood or accepted. We are considered too young to be ill for the rest of our lives, yet we are not expecting cure or recovery. We cannot be granted the time- out that is normally granted to acutely ill (or we were given it at first and have now used it up, overused it), yet we seem to refuse to return to pre- illness life. We are not old enough to have finished making our contributions of productivity and/ or caregiving; old people with chronic illnesses may be seen to be entitled to rest until they die." (Wendell 2001: 21)

From this quotation, the variability and uncertainty of the author's experience of M.E. underscores the theme of *time* as critical to the ways in which some people with changing chronic illnesses feel in relation to wider society. Essentially, some people with illnesses and/

or disabilities are seen as out of time- or out of pace- with others in society, given that there is changeability in the extent to which they can fit into societal norms. Although some experiences of both chronic illness and disability may be inconsistent with societal expectations about specific bodily capacities, there is a noted difference in the degree of variability associated with living with *either* what is termed as a chronic illness *or* what is termed as a disability.

But the issue of *pace* is fundamental to the categorisation of bodies as either ill or disabled, despite different perceptions about its manifestations. Wendell (1996) explains that if the pace of life quickens then this means that less people can meet the new expectation of what can be done in a day or longer period of time, thereby making more people ill or disabled. In the context of busyness being seen as a key marker of good health and normality (Lingsom, 2008), people who experience variability in their experiences of bodily differences (usually those differences classified as 'chronic illnesses') do not neatly fit into clear-cut conceptions distinguishing health from illness and disability from able-bodiedness. The instability of making a distinction between illness and disability on the basis of temporality is therefore apparent. In the context of people's experiences of negotiating multiple illnesses and/ or disabilities, this already messy categorisation of bodily differences on the basis of time is made even more complicated (as will be discussed in this thesis).

In addition to discussion of this issue of 'work', thinking about the life courses of our bodies (and the changes over time) further undermines distinctions made between the perceived degree of permanence characterising differences between chronic illnesses and disabilities. Whereas disabilities are often seen as more stable over a life course, illness is typically perceived as a disruptive event. This is indicated in Bury's (1982) research on rheumatoid arthritis in which he suggests that becoming ill constitutes a turning point in the life course and specifically in relation to how we understand and narrate our identities. However, the development of both illnesses and disabilities is not of necessarily always 'disruptive' and particularly not so when living with multiple illnesses and/ or disabilities. Williams (2000) highlights how illness may already be part of a person's life and identity. Therefore, the development of multiple illnesses and/ or disabilities does not always present a straightforward disruption to life. Experiences of both chronic illnesses and disabilities must be understood as highly variable.

A complementary concept of 'biographical reinforcement' highlights a different mode through which chronic illness and/ or disability may impact identity. In research about the experiences of people living with HIV, it was found that certain aspects of identity in place prior to an HIV infection were actually reinforced after diagnosis (Carricaburu and Pierret,

1995). Indeed, it may also be the case that forms of biographical disruption and biographical reinforcement occur concurrently. In Wilson's (2007) research on HIV and motherhood, mothers stressed the imperative for them to stay alive for their children's sake. Here, biographical disruption is evident (from the fact that their identities are now shaped by a need to access treatment in order to stay alive) as well as biographical reinforcement of their identities as good mothers who want to be there for their children. Discussing the utility of the concepts of biographical disruption and biographical reinforcement as part of the life course again highlights the centrality of theorisations of time to our formation of ill and disabled identities. These theorisations, as has been demonstrated, weaken the easy distinctions often made between (more variable) chronic illnesses and (more permanent) disabilities.

Clearly, a perspective that understands illness as potentially changeable whilst associating disability with permanence ignores the complex trajectories of our individual and collective bodily capacities. This is especially important if we briefly consider how time may be theorised in relation to our bodies. My starting point, follows Butler's (2008) discussion of the multiplicities of time:

"... there is no one time, that the question of what time this is, already divides us, has to do with which histories have turned out to be formative, how they intersect- or fail to intersect with other histories- and so with a question of the how temporality is organized along spatial lines." (Butler, 2008: 1)

There is no one temporal trajectory that we are all part of: disabled bodies are not straightforwardly and 'permanently' that way and in opposition to more variable, ill bodies. A deterministic approach may associate particular bodies with particular temporal trajectories, but this is inconsistent with the variability in how we understand our own pasts, presents and futures. For example, whilst long- term plans may be reined in, changed or abandoned as a result of chronic bodily pain (Bissell, 2009a), there are also many other individual and collective pasts and presents that help shape people's fluid and often uncertain conceptions of possible futures. It is this multiplicity and complexity in the experiences of time amongst people with multiple illnesses and/ or disabilities that I think it is valuable to explore.

In this first part of the literature review, it has been argued that our lack of understanding about the experiences of people living with multiple illnesses and/ or disabilities is a reflection of a societal distinction typically made between chronic illnesses and disabilities. *This distinction is premised on a perception that chronic illnesses are often invisible and*

*variable; whilst disabilities are visible and unchanging.* By no means are these the only ways in which distinctions are made between illnesses and disabilities, but in the limited space available here, issues of visibility and time are argued to be key methods of categorising forms of bodily difference. Whilst this wider societal understanding of the differences between illnesses and disabilities partly explains the lack of research about this topic, a tacit acceptance and reinforcement of the perceived differences between the two terms has meant that people experiencing multiple illnesses and/ or disabilities have been routinely neglected in academic enquiries thus far.

## 2.3 The academic gap between understandings of illness and disability

Alongside this acceptance of wider societal distinctions made between chronic illnesses and disabilities, the gap in the literature is also a reflection of the differing traditions in the social sciences and disability studies literature. Specifically, this gap is shaped by often contrasting epistemological paradigms that hierarchize particular ways, means and forms of knowing. In this section the implications of the epistemological differences between the two sets of literature will be explored with the aim of further highlighting that the choice to study bodily difference as *either* a disability *or* a chronic illness silences the voices of those with *both* invisible and variable chronic illnesses and visible and permanent disabilities.

Although there is no singular epistemological approach that *completely* forms the basis of either the study of health in the social sciences or the study of disability in disability studies, there are certainly differing epistemological paradigms evident from an overview of both bodies of literature. Indeed, disability studies emerged as a discipline as a result of anger about the way people with disabilities were treated by society in general and by the social sciences in particular (Watson, 2012). In the early 1990s, Oliver (1992) posed a defining question to those conducting disability research:

“... do researchers wish to join with disabled people and use their expertise and skills in their struggles against oppression or do they wish to continue to use these skills and expertise in ways in which disabled people find oppressive?” (Oliver, 1992: 102)

Clearly, Oliver (1992) understood the relationship between disability studies and the social sciences to be both problematic and tense. A key objection that disability studies scholars directed at traditional social science approaches was the means through which knowledge was generated about people with disabilities (Oliver, 1992). Disability studies scholars were proponents of ‘emancipatory research’ in which the social relations engrained in the

processes of research production were reconfigured to support the empowerment of people with disabilities (Barnes, 2003). Of course this difference in approach was important because it revealed the seeming contrast in priorities of those conducting research (Goodley, 2010).

The emancipatory research paradigm promoted by disability studies researchers was deliberately framed in stark contrast to the approach taken in the broader social sciences towards the study of illness/ disability. This is evident from Abberley's (1987) criticism of the sociology department at the University of Warwick during the 1980s. Whilst the discipline was increasingly aware of and began to critique traditions of sexism and racism, sociologists did not change their approach to the study of disability (Abberley, 1987). At the time, the burgeoning disability studies discipline was very much separate from the medicine-based "cure or care" (Finkelstein, 1998: 33) disciplines in which the 'experts' were afforded high status (Finkelstein, 1998). Given this situation, the use of an emancipatory approach that fully involved people with disabilities in the research process (Barnes, 2008) became a hallmark of the division between the social sciences and disability studies.

This epistemological difference is certainly evident with reference to the controversy surrounding the publication of research conducted by social scientists in the early 1970s. Some disabled residents of Le Court Cheshire Home in the south of England asked academics to carry out research about life in the home (Miller and Gwynne, 1972). The residents were concerned about the control that staff exercised over residents in many aspects of their lives, including choices about participation in leisure activities and the strict control of their daily routines (Barnes, 2008). This power inequality in homes for people with disabilities was later described by Paul Hunt- who was a resident of Le Court Cheshire Home at the time Miller and Gwynne conducted their research:

"In the hospitals and Homes I have lived in one rarely sees any physical cruelty. But I have experienced enough of other kinds of subtly corrupting behaviour. There are administrators and matrons who have had people removed on slight pretexts, who try to break up ordinary friendships if they don't approve of them. There are the staff who bully those who cannot complain, who dictate what clothes people should wear, who switch the television off in the middle of a programme, and will take away 'privileges' (like getting up for the day) when they choose. Then there are the visitors who automatically assume an authority over us and interfere without regard for our wishes." (Hunt 1966: 12)

The inclusion of this detailed quotation underscores the many and various aspects of disabled people's lives that were controlled by staff at homes such as Le Court Cheshire Home. Despite this, Miller and Gwynne's (1972) sociological study concluded that the residents' call for more inclusion of their views in the running of the home was impractical

(Barnes, 2008). It was following this finding that Hunt (1981) expressed his anger about Miller and Gwynne's (1972) collusion with the medical model of disability in their research, rather than paying attention to the oppressive social conditions in which people with disabilities live. Given the failure of these social scientists to speak out against the regime that staff adopted in the home, an emancipatory research approach became a key characteristic of both the disability studies discipline (Watson, 2012) and the marked division between social scientists and disability studies academics.

Just as disability studies academics criticised the conventional way in which social scientists studied disability; there were also problems with this emancipatory research approach. Whilst Oliver (1992) advocated the inclusion of disabled people in the research process, this meant theoretical research was not valued as much in the disability studies discipline (Watson, 2012). Understandably, there was a concern that research needed to be of material benefit to people with disabilities (Watson, 2012) in light of the historical treatment of them by academics (as previously demonstrated with reference to the residents of Le Court Cheshire Home). But this lack of theoretical reflection led, in some respects, to disability studies creating new and problematic boundaries demarcating acceptable topics of research from those that did not neatly fit into the emancipatory paradigm.

For example, disability studies research has tended to reinforce the idea that mental health problems and intellectual disabilities are the least acceptable conditions to society (Dear *et al.* 1997) by failing to focus on the experiences of those groups of people. The discipline has traditionally focused on the experiences of people with physical disabilities (Thomas, 2007), excluding groups such as those with mental health problems (Moras, 2013 and Thomas, 2007), and/ or intellectual disabilities (Ward, 1997). Clearly then, it is no surprise that disability theory has been portrayed as:

“privileg[ing] masculinist notions of presence, visibility, material ‘reality’, and identity as ‘given’.” (Corker, 2001: 34)

The dominance of the emancipatory paradigm has been a key driver within disability studies (Barnes, 2003), but this has also resulted in the silencing of voices whose lives cannot be improved by making physical, societal changes (for example, improving physical access to public buildings). Unfortunately, then, a key similarity between disability studies and the social sciences is that both have problematically sought to ‘other’ particular bodies. Whilst the emancipatory approach is dominant within disability studies, this is premised on a problematic re- drawing of the boundaries of bodily difference that the development of disability studies itself sought to challenge.

A second way in which the academic divide between the social sciences and disability studies can be understood is with reference to the extent of the centrality of the body as a theoretical framework informing research practices. From the early 1980s onwards, the social science disciplines began to pay attention to bodies (Shilling, 2007); early examples across the different disciplines include Dorn and Laws (1994) in geography; Featherstone and Turner (1995) in sociology and Lock (1993) in anthropology. Although a focus on bodies has been much more pervasive in recent times, including in human geography (see for example Hansen and Philo (2007); Longhurst (2001); Parr (2001)), it is notable that whilst the “rise of the body” (Shilling, 2007: 1) became increasingly important in the pre- millennium social sciences, disability studies did not immediately follow this path (Shakespeare and Watson, 2001).

At the time, disability studies academics were developing a social model of disability as an alternative to the dominant and problematic medical model of disability. Whereas advocates of the medical model of disability start from an assumption that functional limitations (deviating from the societal norm) are to be treated, even cured, through medical and technological interventions, social model proponents foreground the societal barriers (such as social, geographical, political and legal barriers) that act to disable some bodies rather than others (Riddle, 2013). The medical model is based on the idea that a homogeneous societal norm should be upheld and goes hand in hand with the supposed desirability of mending, masking and monitoring aspects of disabled people’s bodies (Davis, 1999). The application of this model has meant that problematic procedures have been conducted on bodies that deviate from the societal norm (Davis, 1999). For example, by compelling people with mobility impairments to use prosthetics in order to walk ‘properly’ and putting cochlear implants in deaf people (Davis, 1999). Thus the medical model is predicated on the desirability of re (producing) normalcy, something which the social model of disability sought to challenge (Davis, 1997).

Advocates of a social model perspective argue that the ‘problem’ does not lie in the person with a disability, but rather with a privileging of normalcy that creates the ‘challenge’ of disability (Davis, 1997). Shakespeare and Watson (2001), two of the leading advocates of the social model, argued that the model was significant in the British disability movement in two key ways. Firstly, implicit within the model was a specific political aim of breaking down disabling barriers (Shakespeare and Watson, 2001). In much the same way as racism and sexism were problematised, so too was discrimination against people with disabilities (Shakespeare and Watson, 2001). Secondly, the social model of disability changed the way in which some disabled people saw themselves (Shakespeare and Watson, 2001). No longer did some people with bodily impairments think that they needed to adapt to society;



instead, they campaigned to change oppressive societal systems (Shakespeare and Watson, 2001). The impact of the social model should certainly not be underestimated, as Crow (1996) explains in relation to her own experience:

“For years now this social model of disability has enabled me to confront, survive and even surmount countless situations of exclusion and discrimination. It has been my mainstay, as it has been for the wider disabled people's movement. It has enabled a vision of ourselves free from the constraints of disability (oppression) and provided a direction for our commitment to social change. It has played a central role in promoting disabled people's individual self-worth, collective identity and political organisation. I don't think it is an exaggeration to say that the social model has saved lives.” (Crow, 1996: 207).

However, straight- forward acceptance of the social model of disability requires researchers to distance themselves from theoretical insights that have been made about bodies within the broader social sciences. The model itself relies on dichotomies that have typically been challenged within the broader social sciences, such as between the body/ society and impairment/ disability (Hughes and Paterson, 1997). More specifically, the social model of disability places emphasis on the difference between an impairment (a feature of an individual body and/ or mind) and disability (the relationship between a person with an impairment and wider society) (Shakespeare and Watson, 2001). But making such a neat distinction between individual bodily differences and societal structures is problematic.

As a key aspect of the social model of disability, the separation of the ‘impairment’ from ‘disability’ has resulted in a neglect of the voices of people who experience bodily troubles, such as pain, exhaustion, coordination problems and neurological differences, amongst many others. Significantly, Morris (2001) explains that although separation of the concepts should have still enabled discussion of impairment experiences, the articulation of any difficulties was risky for her because it could be perceived as perpetuating the medical model of disability. She felt that if she expressed these difficult bodily experiences it could undermine the campaign to make society more inclusive. There was a real fear that voicing experiences of problematic bodily differences would mean that non- disabled people would then say: “there you are then, we always knew that your lives weren't worth living” (Morris, 2001: 10). Given this context, it is unsurprising that many people with disabilities focused on promoting a social model of disability. But if people living with impairments do not discuss their bodily problems, there is a concern that others (for example, those working in health and support services) will continue to operate in ways that do not take into account the full range of experiences of people living with disabilities (Morris, 2001). Thus, for various understandable reasons, the attention that was increasingly being given to bodies within the

broader social sciences in the early '90s was not visible in disability studies. This distinction between different disciplinary fields has resulted in much research on related or complementary substantive topics being approached from very different starting points. But whilst disability studies focused on the social model of disability and the broader social sciences focused on bodies, the experiences of people living with both (visible, permanent) disabilities and (invisible, variable) illnesses fell between the various engagements and, as a consequence, became neglected.

In later years, some within disability studies (such as Morris 2001) argued that although the social model of disability had been helpful, it could not be sustained in its current form. At the same time as publically campaigning to remove disabling societal barriers, some disability activists felt that the expression of pain and other bodily difficulties was banished to the private sphere (Shakespeare and Watson, 2001). However, Oliver (1996) claims that the experience of impairment has never been denied within disability studies, but rather that a deliberate attempt was made to focus on aspects of society that could be changed. However, this idea is based on the assumption that the needs of disabled people are homogeneous (Pinder, 1996). Consequently, not only have particular bodily differences (for example, chronic pain) been excluded from the disability movement, but the problematic notion that it is possible to separate out our bodies from society has been perpetuated.

There is certainly a scalar politics at play here too. It would be more useful to work towards an understanding of disability as concurrently operating at multiple scales, rather than problematically separating out bodily experiences from societal structures. Referring to the concept of psycho- emotional disablism (Reeve, 2002) is useful in highlighting this point. Reeve (2009a) argues that there are two types of disablism - structural and psycho-emotional. We are aware of the idea of structural disablism with its roots in the social model of disability. However, as Hall (2004) identifies in his exploration of social inclusion and exclusion of people with learning disabilities, discussion of inclusion in the mainstream sometimes translates as pressure for bodily behaviours to conform to 'normal' expectations. In practice, if a person contravenes expected standards of normalcy then this can lead to psycho-emotional disablism- whereby disabled people may experience psychological distress because they are made to feel valueless and ashamed (Reeve, 2002). The concept of psycho- emotional disablism is consistent with the idea that society accepts and reinforces a pecking order of bodily experiences and appearances (Thomson, 1997). Hierarchical and clear- cut valuations of particular bodies ignore the ambivalence of people's experiences, including the fact that structural and psycho- emotional disablism are intimately linked and felt through bodies.

For instance, in the UK (and in some other places around the world) there is a new method of street design called 'shared space' in which material infrastructure is used to eradicate the separation of different types of road and pavement users (Imrie, 2012). Imrie's (2012) research demonstrates that some people with visual impairments are not in favour of the creation of such spaces because the reliance on eye contact between different users of the space puts their safety under threat. One respondent understood shared spaces as "full of danger... to be avoided" (Imrie, 2012: 27). This fear and avoidance indicates that psycho-emotional disablism, which is manifest as danger in this case, and the structural design of the urban landscape work together to make 'shared space' inaccessible to some users. Such vulnerability of bodies to one another and to different environments further underscores the difficulty associated with separating 'impairments' from 'disabilities'.

In this section, the academic gap between the study of 'disability' and 'chronic illness' has been explored, specifically with reference to the centrality of both the social model of disability (in disability studies) and bodies (in the broader social sciences). These differing foundations and traditions within the two disciplines have implications for how researchers approach the study of bodily differences today. In the discussion presented in this section and the previous section, I have demonstrated how the societal and academic gaps between our understandings of chronic illness and our understandings of disability become apparent in some quite subtle, but important ways. I argue that this gap meant that whilst disability studies focused on visible and stable forms of bodily difference; the social sciences paid attention to more invisible and unstable forms of bodily difference- with neither discipline considering the experiences of bodies of those people living with both illnesses and disabilities. The attempt to isolate particular illnesses or particular disabilities within bodies has led to the neglect of people negotiating multiple illnesses and/ or disabilities.

## 2.4 Bridging the gap

But it is also possible to challenge the gap between our understandings of illness and understandings of disability through reflection on some of the themes discussed *across* the health and disability literature. Although the two sets of literature have taken different perspectives to the study of bodily differences in the past, both have shaped the approach taken in this thesis towards exploring the experiences of people negotiating multiple illnesses and/ or disabilities. Despite some of the tensions between disability studies and the broader social sciences (discussed in the previous sections), there are also some commonalities. It is the purpose of this section to set out how this existing literature has

shaped some of the key ideas influencing my research and how, in turn, this thesis will (modestly) contribute towards the furthering of knowledge about specific aspects of illness and disability experience.

To achieve this end, I would like to discuss two key ideas from the literature that frame the work presented in this research. Again, although there are many different influences on this research, within this section it is only possible to discuss some of these. In the next chapter, further detail is provided about some of the epistemological considerations that are important to understanding the work of this thesis. In this section, however, I will focus on issues related to how we can think about illness and disability experiences, based on my reading across the social sciences and disability studies literature. Specifically, these ideas are:

a) **The inability to isolate a particular symptom within a body** through discussion of the importance of 'other' experiences shaping people's identities, including, but not limited to issues of gender, race, class, space, time, personalities, histories, geographies, the development of multiple 'symptoms' and relationships between bodies.

b) **The political and moral ordering of illness and disability** through an exploration of processes shaping the (re) production of legitimate and illegitimate bodily experiences across time and space.

In relation to the first of these ideas, this thesis is heavily influenced by the literature that links particular experiences of bodily differences to much broader social and geographical contexts. Although illness and disability experiences are not the same for everyone, they are lived out in particular ways, at particular times and in particular spaces. For example, any particular symptom is imagined, felt and communicated within the context of constantly negotiating a politics of inclusion and exclusion. Much of the existing literature across the social sciences (including disability studies) has emphasised the ways in which illness and disability experiences are tied to a sense of belonging in particular social spaces. The isolation of any one symptom in a body is impossible given this context.

An important contribution that human geography has made to research is through the work linking the concept of 'therapeutic landscapes' with mental wellbeing. This body of literature has concentrated on the relationships between particular types of landscapes, such as woodland (Milligan and Bingley, 2007) and home spaces (Williams, 2002), and possible improvements to mental wellbeing. The suggestion that 'therapeutic landscapes' can improve mental wellbeing has also been used as a framework to evaluate hospital designs in the UK (Gesler *et al.* 2004, Curtis *et al.* 2007). Linking together our understandings of both the physical and social dynamics of such places emphasises the importance of understanding the context in which any one 'symptom' is felt, including the opportunities that

may be offered for improved mental health in some places more than others. This field has sought to demonstrate a nuanced approach to our understanding of the extent to which particular landscapes might have positive impacts on wellbeing. Indeed, through her research on garden work for people with mental health problems, Parr (2007) suggests a move away from post-positivist approaches to the geographies of health, including to the straight-forward application of the term 'therapeutic landscape', in favour of greater focus on people's embodied and complex relations with particular landscapes. Similarly, Andrews (2004) argues that the concept of 'therapeutic landscapes' has been mainly understood and explored in relation to physical spaces rather than the imagined spaces that may be important for both patients and staff in therapeutic settings. Hence, not only must illness and disability experiences be understood in relation to broader social and environmental contexts, but also in relation to an awareness of the complexities and changeability of such experiences, spaces and bodies.

This is particularly apparent if we reflect on ideas of inclusion and exclusion more closely. What some people consider 'inclusive' may differ from other people's perspectives. For example, social relations formed in public space can foster community spirit and provide respite from the routine of daily life for some people (Cattell *et al.* 2008) but for others it can be fraught with difficulty. Lingsom (2012), an academic who writes about her own illness and disability experiences, explains that she feels a heightened sense of difference from others and from her pre-injury self when occupying public spaces. Specifically, she experiences relentless social pressure to participate in activities, given that able-bodied people always seem to be going places and doing things (Lingsom, 2012). For Lingsom (2012), negotiating pain and fatigue mean that the value of participation in public spaces is subject to constant (re) assessment (Lingsom, 2012). The entrenched significance placed on participation and 'busyness' provokes us to question the extent to which people living with illnesses and disabilities feel a sense of belonging to public spaces. Power dynamics are a particularly important aspect to such processes, with Kitchin (1998) suggesting that:

"Spaces are currently organised to keep disabled people 'in their place' and 'written' to convey to disabled people that they are 'out of place'." (Kitchin, 1998: 343).

Lingsom's (2012) experiences of bodily difference are, therefore, intimately tied to the power relations (re) produced in particular spaces. Clearly, symptoms of illnesses and disabilities are not 'isolated' within the body; they are lived and felt in relation to other expected social norms.

This sense of difference from the norm is also experienced in domestic settings by some people with disabilities. Feelings about 'home' are related to expected bodily functions,

mobilities and capacities (Imrie, 2004). Importantly, in Dyck *et al.*'s (2005) study of home as a site of long-term care, the authors note that the onset of illness, impairment or disability can mean changes in the way home is understood. The home may become more public as it is reimagined and reordered as a site of labour for carers, resulting in a blurring of thresholds between public and private (Dyck *et al.* 2005). In this sense, illness and disability experiences are understood as intimately tied to our identities and emotions. For example, this idea is well explained with reference to a description of the care provided to a 66-year old woman with M.S. called Christina (who lives in Ontario, Canada):

“Christina endured considerable vulnerability in terms of bodily safety and care. She was dependent on a caregiver for most basic bodily and social needs—from catheterization, lifting in and out of bed, to appearing as socially ‘appropriate’. For her, the vulnerability of the physical body is closely tied to waiting for an attendant to look after her needs. A personal support worker puts her to bed at 8 or 9 p.m. where she remains until the worker returns at 8 a.m. the next day. She recounted how sometimes she gets bladder spasms at night, and despite the catheter, the urine leaks and she must then lie all night in wet sheets. The worker launders the sheets (outside the job description) so that they are not left lying around until the next time the homemaker comes. Her care requires the ultimate invasion of privacy; being seen naked, invasion of the body with a catheter, loss of control of body wastes and their handling. These invasions spill over into the ability to perform a social persona—with a crossing of gender boundaries, as well as those of homespace management, when she has a male personal support worker.” (Dyck *et al.* 2005: 180)

There are many important themes mentioned in this quotation (including issues of gender, care and labour), but here I would like to focus on the disruption of boundaries between public and private and the implications this has for societal expectations and identities. In the context of an able-bodied societal norm that often equates home with ideas of security and privacy (Imrie, 2004), reflection on the experiences of those who develop illnesses or disabilities requiring care (Dyck *et al.* 2005) underscores home as a fluid space with multiple possible meanings (Imrie, 2004, Moss, 1997). This discussion of home spaces underscores the processes of inclusion and exclusion in particular spaces as important to the (re) production of identities, but also shows the vulnerability and changeability of such identities. Christina's experience, for instance, prompts us to consider issues of independence, dependence and inter-dependence in seeking to understand illness and disability experiences.

In the first part of this section, I have sought to demonstrate why the isolation of a particular symptom, illness or disability within a body is not possible. Negotiating illnesses

and disabilities is highly relational and emotional, with significant implications for other aspects of people's lives and identities. This was shown with reference to the social aspects of negotiating feelings of inclusion and exclusion in a variety of spaces, including 'therapeutic' landscapes, public spaces and home spaces. Through this discussion, the spatial unevenness of illness and disability experiences becomes clear- prompting us to consider how and why particular bodies are perceived to belong in particular spaces at particular times and what implications this has for negotiating identities.

This focus on broader identities is something that *both* the existing disability studies and social sciences literature has placed emphasis on. For example, there are several articles linking chronic illness and/ or disability with issues of gender (Meekosha and Dowse, 1997, Dyck, 1995) and sexuality (Sakellariou, 2006, Anderson and Kitchin, 2000, Sothern, 2007, Shildrick, 2007). Alongside this important work, the starting point of my thesis is my assertion that there is scope to consider the implications of negotiating *multiple* illness and/ or disability identities. Rather than isolating a particular illness or disability within a body and then relating it to issues such as gender, class, geographies or histories, I think it is also important to think about the complexities, ambiguities and conflicts that often characterise people's experiences of negotiating multiple illnesses and/ or disabilities. Hence, the existing social sciences and disability studies literature prompts consideration of how illness and disability experiences are related to much broader issues (such as power, identity and relationships) and this thesis will seek to contribute to and further that idea by focusing on the bodies and lives of a group of people whose perspectives have been largely absent from academia.

As well as this issue of identity being a common concern of both disability studies and the broader social sciences, a second point of contact between the disciplines is a focus on the political and moral ordering of illness and disability experiences. Following the work of Charmaz (1999), this thesis has been shaped by the idea that experiences and understandings of illness and disability are shaped by notions of morality. In the remainder of this section, I explore such shaping specifically in relation to themes of: disclosure; pity and 'alternative' spaces as discussed across disability studies and the broader social sciences. It is within the context of the existing literature's focus on the links of various notions of morality with illness and disability experiences that forms an important basis on which the work of this thesis is offered.

As the first of three themes, disclosure of illness and disability experiences is heavily associated with negotiations of morality. Charmaz (2002) explains that many people living with chronic illnesses keep their difficulties hidden from others at certain times and in certain

spaces. For instance, in research with university students in the United States, it was found that people with disabilities tried to manage the space and time of disability disclosure (Olney and Brockelman, 2003). This is unsurprising, given the inferiority with which disabled people's bodies are often perceived by those embodying 'normality' (Edwards and Imrie, 2003). This link between morality and decisions around disclosure is an important aspect of the lives of many people negotiating illnesses and disabilities.

Within this moral framework, there are several reasons why people with illnesses and disabilities may choose to be strategic about disclosing their experiences. Silence may be necessary if it is felt that (i) others won't understand their experiences, (ii) it would harm others who learn about their illness, (iii) the cost of disclosure would be too great or (iv) others are not interested to hear about their illness experiences (Charmaz, 2002). These negotiated and relational aspects of articulating illness and disability experiences have to be considered alongside the potential for stigmatising episodes to occur. This complex process is evident with reference to Salmon's (2012) research in which young people with disabilities in Nova Scotia were not considered as *potential* friends by non-disabled young people. Instead stigma and social isolation had to be constantly negotiated in friendship circles, resulting in some of the research participants being unable to form long-term friendships (Salmon, 2012).

Accompanying the difficult negotiation of communication about illness and disability experiences; moral ordering practices also feature in shaping understandings about these experiences. For example, despite a basis in ideas of objectivity, medical encounters are often orientated according to clinicians' judgements about patient age, class and gender (Lupton, 2003). Even decisions about what clothes are worn and what make-up is applied were important to patients in trying to emphasise their credibility during clinical encounters, as demonstrated in research with women experiencing pain in Norway (Werner and Malterud, 2003). Far from a neatly objective and clinical setting, medical encounters are places in which moral hierarchies are at work. Therefore, any 'disclosure' takes place in the context of knowledge about how people with illnesses and disabilities may be treated, even in supposedly 'objective' clinical settings.

It is also important to emphasise that the disclosure of particular illnesses or disabilities often has particular moral dimensions that should be considered. For example, in Lupton's (1999) analysis of the depiction of people with HIV/ AIDS in the Australian media between 1994 and 1996, she found that although people were judged on the basis of how they contracted the virus, evaluations were also based on how they conducted themselves once diagnosed with HIV. Clearly, in this sense, a diagnosis of HIV is often perceived in moral



terms in which people's behaviour does have an impact on the extent to which illness experiences are understood and accepted. Hence, negotiations about the disclosure of any illness are not only rooted in notions of morality in particular spaces (such as in clinical settings), but also in relation to the particular type of illness or disability that a person experiences. The link between morality and disclosure is a topic that has emerged to feature quite prominently in this thesis, as, for example, in *Chapter 4* where the moral ordering at play was significant for people in negotiating the disclosure of multiple, complex and (sometimes) conflicting forms of bodily difference.

A second facet of this discussion about the moral ordering of illnesses and disabilities centres on the (re) production of feelings of pity and other problematic emotions, such as fear and blame, that are often attached to people living with illnesses and disabilities. Pity, for instance, has to be understood as part of a social pecking order in which those expressing the emotion subordinate the 'receivers' of it (Hughes, 2012). By projecting pity onto those with disabilities, non-disabled people can successfully prop up their societal position as compassionate and generous (Hughes, 2012). Such moral judgements form an integral component of our knowledge about and response to the presence of illness and disability.

This moralising discourse is evident from the way in which many people narrate their experiences of bodily differences. In Werner *et al.*'s (2004) research with women with chronic muscular pain, the participants used several techniques to communicate their morality. For example, as people with unexplained pain, participants often contrasted their own illness experiences with others who have similar pain. One participant described herself as a 'positive person' and noted that:

"I always think that 'OK, we'll manage that, won't we?' while the other [participants] tended to say: 'I don't know': They haven't budged for thirty years, and thought it was the end of the world to do weight lifting or anything like that. (...) I've always been a positive person, or so I believe. So I make the best of things, and do as well as I can' (I, 37 years)." (Werner *et al.* 2004: 1040)

Clearly it was important to this participant to emphasise that she was really trying to cope with her pain. One way this could be achieved was by distancing herself from the efforts of other people, thus projecting herself as a morally acceptable subject (Werner *et al.* 2004). Hence, we see attempts by the participants to re-partition the moral boundaries that are often attached onto people with illnesses and disabilities- as a reflection of the wider judgements that are constantly made about this group of people. As a key idea in this research, the existing literature across the disability studies and broader social sciences

literature emphasises the importance of the projection of particular, and mainly negative, emotions onto ill and disabled bodies. This idea will be discussed in more detail at various points in the thesis, including in *Chapter 5* s focus on participants' diagnosis and treatment experiences.

A third sub- topic explored in the existing literature centres on some of the implications negotiating these moral dimensions for illness and disability experiences. For example, as a result of the exclusion that some people negotiating disabilities face, alternative spaces of inclusion are being formed (Hall, 2005). In his research with people with learning disabilities in Scotland, Hall (2005) writes about the role of care homes as sites of refuge and inclusion for some. Despite the establishment of such 'segregated' spaces going against the grain of current policy makers, because of the negative connotations associated with such a 'lack' of independence, it is interesting that some participants in Hall's research found these spaces to enhance the quality of their lives. But, importantly, the creation of such spaces must be put in the context of the difficulties that people with learning disabilities sometimes encounter in trying to access other types of spaces (Hall, 2005).

Given the risks associated with trying to access spaces which are routinely exclusionary, it is no surprise that sites of refuge are sought by people living with a range of illnesses and disabilities. In relation to the development of online communities for people with mental health problems and those of the autism spectrum (AS), Davidson and Henderson (2010) posit the idea that the creation of such spaces could be a reflection of a "crisis of 'real-space' community" (Davidson and Henderson, 2010: 66). Such 'real spaces' may be disabling to people with mental health problems and people on the AS because of the associated emotional stress, sensorial overload and stigma (Davidson and Henderson 2010). Hence, one response to the moral ordering processes that devalue the bodies of people with illnesses and disabilities is the creation of spaces of inclusion, such as care homes and online communities. As is evident from this discussion, a focus on the ways in which people respond to the moral dimensions of negotiating illnesses and disabilities has been important in the disability studies and broader social sciences literature. This idea shapes the approach taken to the study of multiple illness and disability experiences in this thesis. For example, in *Chapter 6* I explore how such moralities shape the mobilities of participants in this research.

Alongside the discussion presented in the first part of this section about the importance of exploring the broader dimensions of illness and disability experiences and identities, the second part of the section has set out the influence that the existing literature about the moral considerations associated with negotiating such experiences has on my research.

Specifically, discussion of two ideas that cut across the disability studies and broader social sciences literature underscores some complimentary aspects of two sets of literature that are frequently thought of to be at odds (as explored in the first two sections of this chapter). I have also been able to briefly highlight some of the ways in which my research will seek to contribute towards furthering these ideas.

Through the discussion presented in this chapter, the work of this thesis also becomes situated within the broader mental health literature. My critique of tendencies to try to 'isolate' symptoms within bodies is particularly applicable to much of the mental health research referred to in this chapter. For example, my emphasis on the importance of *multiplicity* is shaped by- and hopefully contributes to- research that focuses on complex relations between bodies and landscapes, discussed by Parr (2007) and others in the context of work on 'therapeutic' landscapes. Paying attention to the multiplicity of people's bodily experiences not only destabilises tendencies to separate bodies from landscapes, but also the idea that physical illness can be separated from mental illness. The work of this thesis problematizes the isolation of any one symptom, illness or disability within the body: an important contribution to mental health research that seeks to include the voices of those who experience multiple illnesses and/ or disabilities.

In conclusion to this chapter, I have sought to demonstrate both the opportunities and challenges that the existing literature presents for this research. Although, it is clear that there are important reasons why the voices of people with multiple illnesses and/ or disabilities have not been heard within academia, this practice needs to be challenged. Whilst some researchers have focused on disability and others have focused on illness, there has been a neglect of people with both illnesses and disabilities because they undermine existing academic and societal boundaries about the nature of bodily differences. Thus, in terms of the existing literature, it is evident that there is a gap that it would be beneficial to address. In order to achieve this, there are substantial gains to be made from considering existing ideas from the literature (as was particularly demonstrated in the final section on this chapter). Consistent with this, I have integrated ideas from the literature with the analysis presented in this research. The approach taken to this thesis is, therefore, rooted in an awareness of both the opportunities and challenges that the existing literature presents for exploring the experiences of people negotiating multiple illnesses and/ or disabilities.

## Chapter 3: Methodology

### 3.1 Feminist epistemologies

As part of an effort to ‘bridge the gap’ in our understandings of the lives of those living with multiple illnesses and /or disabilities (explored in the last section of the previous chapter), this thesis will draw heavily on feminist theories, methods and practices. Feminist epistemologies offer modes of thinking and doing that challenge the exclusion of particular people, such as those whose experiences are the focus of this research, from academic thought. Following the suggestion of Madge *et al.* (1997), there are three aspects to feminist geographers’ contestation of dominant and problematic ideas about how research should be designed. Firstly, it is important to critically reflect on the ideas and assumptions underpinning the development of theories within the discipline (Madge *et al.* 1997). Secondly, the methods used to examine research topics and, thirdly, the ways in which topics deemed suitable for research are developed both need to be interrogated (Madge *et al.* 1997). The focus of this chapter is mainly on the second of these aspects of research design: the methodological considerations associated with conducting this project. However, the first section of the chapter explores important aspects of the feminist epistemological approach underpinning this research, before further discussion is presented about how these ideas informed the design and practice of this research.

For me, taking a feminist approach to the study of people’s illness and disability experiences means paying attention to ideas of (i) reflexivity, (ii) positionality and (iii) scepticism of clear-cut categorisations. Although there are many other ideas that have shaped this research, it is beyond the scope of this project (and any project) to explain all of these in great detail. Instead, exploration of these three crucial ideas enables an (albeit limited) understanding of the most influential feminist theories and concepts underpinning this thesis. The first of these is the idea of reflexivity. As Bondi (2009) suggests, conducting research in a reflexive way means paying attention to the processes through which knowledge is produced, amid the complex power relations between researchers and participants. This reflexivity involves challenging problematic research practices, but also realising that such structural inequalities between particular individuals and groups of people are not easily changed (Bondi 2009).

One important opportunity that a feminist focus on reflexivity offers within the context of this research is consideration of how people living with illnesses and disabilities are typically

viewed in our society. Indeed, conceptions of illness and disability are often based on notions of dependency, weakness and inadequacy. Certainly, the negative characteristics often attached to people living with illnesses and disabilities result in the (re) production of disability as problematic. This view about disability is evident from an extract from a popular Scottish poem about the experiences of a man with disabilities being helped in a snack bar:

“Wherever he could go it would be dark  
and yet he must trust men.  
Without embarrassment or shame  
he must announce his most pitiful needs  
in a public place. No-one sees his face.  
Does he know how frightening he is in his strangeness  
under his mountainous coat, his hands like wet leaves  
stuck to the half-white stick?  
His life depends on many who would evade him.  
But he cannot reckon up the chances,  
having one thing to do,  
to haul his blind hump through the rains of August.  
Dear Christ, to be born for this.”

(Morgan (1968), ‘In the Snack Bar’)

Told from the perspective of a non-disabled person encountering a visibly disabled person in a public space, Morgan situates disability alongside humiliation, fear, dependency and hopelessness. He perpetuates the idea that people with disabilities are both voiceless in society (apart from when “he must announce his most pitiful needs”) and separate from the rest of society. However, there is a level of empathy evident from the poet in that he questions what kind of life it is possible to have, given the disabilities experienced by the man. Of course this empathy or compassion could be simply read as pity but considerable reflection on this has led me to an awareness of the subtleties of depictions of illness and disability. Indeed, although the portrayal of disability may be mostly negative, I also think these depictions can be quite nuanced and even apparently contradictory. It is complexities such as these that make a feminist approach to the study of illness and disability helpful.

Giving voice to some of the contradictions, ambiguities, interdependencies and uncertainties that shape understandings of illness and disability experiences is, surely, an advantage of taking a reflexive approach to research design and practice. As a key pillar of the feminist epistemological framework adopted in this research, this reflexivity also prompts a consideration of the ways in which it could be possible to challenge some of the problematic theorisations of illness and disability discussed above. Within the context of this thesis, an important aspect of taking a reflexive approach to designing research lies not just in acknowledging these problematic conceptions of illness and disability, but also in destabilising the power relationships that bring these about.

Adopting a feminist approach to the study of people's experiences of illness and disability enables interrogation of pervasive- but troublesome- conceptions of bodily difference that 'deviate' from the norm. Certainly, as Thomson (1997) explains:

"... feminism's often conflicting and always complex aims of politicizing the materiality of bodies and rewriting the category of woman combine exactly the methods that should be used to examine disability." (Thomson 1997: 21)

Thus, reflexivity about the difficulties associated with drawing neat distinctions between man/ woman and disabled/ non- disabled encourage many feminists to formulate research that attempts to pay attention to such complexities. This effort is evident throughout my thesis, though the approach is not without its challenges. Indeed, it is important to explain that the relationships between (some) feminists and (some) disability theorists have not always been warm.

The very idea of linking research about illness and disability with feminism was initially overlooked (and even undermined) by both disability and feminist scholars. In the early 1990s, Morris (1992) wrote that feminist theory had broadened to include issues of race and class, but that age and disability were rarely attended to. To back up this claim, Morris (1992) includes an example from a book written by Caroline Ramazanoglu (1989) in which she tries to explain her lack of attention to disabled and older women:

"... while these are crucial areas of oppression for many women, they take different forms in different cultures, and so are difficult to generalise about. They are also forms of difference which could be transformed by changes in consciousness" (Ramazanoglu 1989: 95)

Just as feminist theory failed to incorporate the experiences of people with disabilities; so too did disability studies tend to exclude feminist thought. For example, barriers that have

specific relevance to women with disabilities have typically been overlooked, as Morris (1996, cited in Thomas (1999)) explains:

“Disabled women want personal assistance which enables them to look after children, to run a home, to look after parents or others who need help themselves. In contrast, the disabled people’s movement has tended to focus on personal assistance which enables paid employment and other activities outside the home.” (Morris 1996: 10)

Clearly, whilst feminism has sometimes tended to focus its attention on the needs of non-disabled women; so too has disability activism tended to focus its attention on the needs of disabled men. This has resulted in a situation where the voices of women with disabilities are often not heard. Being reflexive about this legacy of tension between feminism and disability activism is an important consideration shaping the approach taken in this thesis. However, as well as acknowledging this tension, the presentation of this research also highlights some of the benefits of taking a feminist approach to the study of illness and disability experiences. Indeed, as shall be particularly demonstrated in the empirical chapters of this thesis, practicing this feminist idea of reflexivity is fruitful when exploring the complex, uncertain and often ambiguous experiences of people living with multiple illnesses and/ or disabilities.

The second important feminist concept shaping the approach taken in this thesis is that of positionality. The idea that we- as researchers- are not neutral observers of people’s lives is a key aspect of the concept of positionality. Instead, our identities and actions affect processes of knowledge production. For example, Katz (1994) argues that there is a blurring between where ‘the research’ stops and when ‘everyday life’ begins. Indeed, the line between our work and other aspects of our lives is often unclear. This suggestion is fleshed out through reflection on some of the reasons why researchers undertake specific projects. Ellingson (2006) explains that she undertook research about health communication because she could not ignore her own bodily experiences of bone cancer- experiences that include pain and scarring. Our own bodily experiences are not absent in research and there is value in acknowledging and incorporating this into our work. Indeed, in the context of this work, reflecting on our own thoughts and experiences of disability creates a space where we are able to consider (and perhaps act upon) the political nature of personal experience (Worth 2008).

For me, this reflexivity about my own positionality prompts a number of thoughts about issues relevant to conducting this research project. As well as issues relating to my own identity and how this related to participants and others important to this research, such as in respect of age, gender and class, it was also significant when considering broader ‘roles’ I

and others had during the research. For instance, being both a volunteer at the Waddington Street Centre Café and a researcher conducting interviews (discussed more elsewhere in this Chapter) shaped the research interactions that were possible and the kinds of data that were generated. Being both a volunteer and a researcher helped in some ways- particularly because I had more time and opportunity to build relationships and trust with people. At other times, I felt that others were confused by my dual roles. On some occasions, people would forget that I conduct research, as well as volunteering at the WSC.

Some of these issues of positionality are discussed in more depth in other sections of the thesis (for example in Section 3.5. I discuss Michael's perception that I- as a researcher- am not ill/ disabled), but in this section I will provide one in- depth example that is demonstrative of how my own positionality has been important over the course of conducting this project. As a researcher working within the field of geography, I have spent a lot of time considering the apparent divide between the discipline of geography and ideas about illness and disability. During the data generation stage of this project it was clear that the people involved in the research (myself included) understood and communicated ideas about geography in different ways. Reflecting on these differences helps to address a key question that was frequently posed during the course of this research:

“So you would like to hear about experiences of anxiety- how does that relate to geography?” (this question was typically asked by research participants, academics and family/ friends)

There are two interrelated ideas underpinning the proposition of this question. Firstly, it suggests that a range of people I spoke to were unclear about why a project that explores experiences of illness and disability is related to the discipline of geography. Secondly, there is an assumption that- as the researcher- I am well placed to authoritatively identify the relationship/s between what the project seeks to do and why it is linked to geographical concepts. Given this apparent tension between popular and academic understandings of the relevance of geography to the research, it is valuable to explore the ways in which different people involved in the project thought about its conceptual framework. Examination of both the history and current condition of both academic and popular geography is a key part of reflecting on my positionality as someone claiming to be both a geographer and someone interested in people's experiences of illness and disability.

Although I may not view these two positions as inconsistent, some of the people involved in the research did question the connection between the two. In reference to an extract of an interview with a participant called Patrick, the sense that academic and popular geography inhabit “different worlds” (Bonnett 2003: 55) becomes apparent:



*Lindsay: "so, ok, is there anything else that you want to... that you think is quite important to bring up?"*

*Patrick: No, no I'm just trying to get the connection between geography and OCD [obsessive compulsive disorder]. Do you know what I mean? I'm trying to help you out that way. Do you know what i mean? I don't know how it relates to geography- that's my struggle with this. But I've tried to, like say well, you've got memories in certain places.*

*Lindsay: yeh*

*Patrick: and you try and avoid places or go [to] places. And there's certain places that make you feel better.*

*Lindsay: uhu*

#### *LATER IN THE INTERVIEW*

*Patrick: but it would normally be not the place, it would be what's going on.*

*Lindsay: yeh*

*Patrick: do you understand? Unless it was a holiday and different scenery and somewhere I've never seen before. That might distract me enough to lessen it."*

From this quotation, we see that geography's relevance to Patrick's experience of OCD was a "struggle" for him to understand. Evidently, this participant is tapping into a conception of geography underpinned by what Curtis (2010) describes as a 'conventional' view of space. This is where places can be labelled according to geographical boundaries that are organised within euclidian space, usually without mention of social or cultural understandings of space (Curtis 2010).

Such a conventional (or popular) view of geography is evident all around us. For example, the idea that geography is about a collection of facts about the world (Johnston and Sidaway 2004) is propagated in magazines such as National Geographic (Johnston, 2009). This is clear with reference to the magazine's seven editorial principles developed in 1957, as follows:

- "1. Absolute accuracy;*
- 2. Abundance of beautiful, instructive and artistic illustrations;*
- 3. Everything published to have permanent value;*
- 4. All personalities and trivia to be avoided;*

5. *Nothing of a partisan or controversial character;*

6. *Only what is of a kindly nature is printed about any country or people, everything unpleasant or unduly critical being avoided, and*

7. *The content of each issue should be timely.”*

(Grosvenor (1957), cited in Johnston (2009))

Clearly, what is described by Grosvenor (1957) is consistent with a positivist world view in that the aims of National Geographic are to describe the world (based on accurate recording of data generated through sensorial experiences) but also to explain phenomena from a neutral standpoint (Johnston and Sidaway 2004). Although particular strands of the academic discipline- such as population geography- are associated with the empiricist epistemological standpoint (Graham 1999) taken by editors of the magazine, today much of academic human geography is moving away from its associations with the empiricist tradition still dominant in popular geography. But why does it actually matter if people have different understandings of geography and what are the implications of these differences for this project?

It is useful to reflect more deeply about the reasons why geography is popularly imagined in the way Patrick has described (see above). The extract demonstrated that this imagination affected how the participant (Patrick) orientated his answers, as exemplified by his request for clarity on the ways in which his experience of OCD could relate to geography. Popular notions of the nature of geography may not affect how some geographers carry out their day- to- day work but these orientations do influence how other people view the discipline with potential resultant implications for levels of public support and even research funding (Johnston 2009). In the context of this project, I argue that- historically- geographers have contributed to the production, reproduction and legitimation of the ethically problematic practices associated with this popular imagination of the discipline. Crucially, in addressing these histories we begin to reflect on the ways in which alternative geographical practices are possible.

One important aspect of this is the discipline's association with imperialism. Indeed, particular geographical processes of knowledge production provided justification for the exertion of imperial authority over 'others' (Clayton 2000). Specifically focusing on health, this connection between the processes of knowledge production and imperialism is evident with reference to the segregation of white Americans from black Caribbeans in the early 19th Century Panama Canal Zone (Frenkel 1992). In the context of the dominance of the theory of environmental determinism within geography, concerns about health were deployed as a

justification for segregating people along racial lines (Frenkel 1992). The tropical climate of Panama was thought to cause a range of climate specific diseases and was therefore considered an unhealthy place for people of originating from Europe and America to live (Frenkel 1992). Evidently, as a popular theory amongst geographers and others, environmental determinism provided a basis to support accepted imperial and racist ideas and practices (such as segregation), as is evident with reference to the 19th Century Panama Canal Zone.

Given this history, it is hardly surprising that academic geography is trying to move away from the development, use and reproduction of ideas associated with imperialism (Bonnett 2003). However, the consequences of this for the discipline are two- fold. Firstly, it calls into question the extent to which academic geography has actually properly acknowledged and reflected on the discipline's history (Bonnett 2003). Secondly, escaping from the empiricist tradition associated with imperialism has also gone hand in hand with running away from engagement with popular imaginations of geography (Bonnett 2003). It is in this historical context that reflection on my positionality as a geographer is important.

Reflecting on these histories provides a key window to understand the interactions that take place in the present day, as Ahmed (2000) argues:

“... we cannot assume that history is something that can be simply missing from the abstraction of the encounter from the broader social relations that make encounters possible: to do so would turn history into another fetish, into an object that could be present or absent.” (Ahmed 2000: 11)

The kinds of encounters that have the potential to take place in the present day are influenced by the particularity of historical social relations. Further to this point, it is significant to note that those conventions associated with the historical practice of academic geography are visible today. For example, geography research about HIV/ AIDS has been heavily influenced by the cartographic tradition. Through the use of maps, medical geography sought to distance itself from gay men by viewing their bodies as vectors of disease to be plotted on a map (Brown 1995), rather than actually using research methods that explored experiences and complexities of living with the illness (for example). The production and consumption of maps are particular ways of orientating the world that represent and reproduce specific sets of power-laden social relations (Harley 1988), as is apparent from the distance demarcated and reinforced between academic geography and gay men (Brown 1995). Despite this tradition, it is important to note that many contemporary academic geographers are critical of such approaches. For example, Dorling (1998) has discussed the use of 'alternative maps', including cartograms (Dorling 2006). This involves

highlighting inequalities in social relations be re- sizing the territory in correspondence with the variable being mapped. Hence, although legacies of problematic geographical practices are evident in contemporary human geography, these approaches have also been challenged.

Significantly, the emphasis on problematising some geographical traditions has also been steered towards reflecting on the ways in which contemporary geographers actually construct the histories of geography. Being aware of the silence of particular groups of people from historical accounts of the discipline (Rose 1995) brings into focus the embedded power relations associated with any claims to knowledge, given that:

“The writing of certain kinds of pasts is legitimated by, and legitimates, only certain kinds of presents.” (Rose 1995: 414)

Several academics have taken up the task of exploring the lives and contributions of those people previously excluded from descriptions of the history of geography. Typically, the focus on academic geography meant that women were invisible within a framework of scholarly research of masculinist and eurocentric geographical traditions (McEwan 1998). Challenges to this approach are provided in the literature. For example, McEwan (1998) examines the writings of women travellers in West Africa during the late nineteenth century and Maddrell (2008) investigates the importance of women’s geographical work during WWII- highlighting the role women played in the production of Naval Intelligence Handbooks in the U.K., for example. Attending to such “minute and the monumental” narratives (Maddrell 2008: 144) in these instances also means focusing on the history of popular geographies. Certainly, a concentration on the history of academic geography obscures the potential to recover insights about how geographical ideas were deployed and understood by a broader range of people over time and space. However, some work has begun on addressing this gap- such as an exploration of the ways in which the magazine *Revista Geográfica Española* (1938–1977) connected imaginations of national identity (in art, history and travel sections of the magazine) with Franco’s Spain (García-Álvarez and Marías-Martínez 2013). Clearly, problematic geographical traditions have been challenged within the discipline and are forming a basis in which topics and methods of knowledge production are being developed.

Acknowledging and addressing the histories of geography certainly goes a long way to explain the kinds of differences between academic and popular geography evident within this project. Additionally, as this section demonstrates, thinking about this context prompts geographers to consider the association between particular traditions and the kind of work carried out on a day- to- day basis. Crucially for me, this means reflecting on how my

positionality as a geographer influences the research I conducted. As a key aspect of the knowledge production process, our positionalities shape the relationships formed and data generated with participants. Although, I have gone into detail about my positionality as a geographer, other aspects of my identity were important in shaping my project (such as my age, gender and race). As a key part of the feminist approach taken in this thesis, my positionality has therefore certainly shaped the approach taken to this project.

Alongside the ideas of reflexivity and positionality, the third key feminist idea influencing the approach taken to this research is scepticism of clear-cut categorisations. Feminist approaches afford researchers the ability to become attuned to the spaces of ambiguity that feature in many chronically ill and disabled people's lives. People's bodily experiences do not always neatly fit into the paradigms of 'cause and effect' or "well or unwell", as shall be demonstrated in this thesis. Bondi (2004: 5) explores a "politics of ambivalence" whereby spaces may be created in which complexities and inconsistencies are embraced as important to people's lives. There is a degree of force that works in the pursuit of definitive answers, but by critiquing the relationships at work in the quest for these definitive answers, we realise that there is a lot to be learnt about the lives of chronically ill and/ or disabled people.

One such relationship is that between the researcher and participant in which experiences may not be fully understood or communicated by either party. For example, as was discussed in *Chapter 2*, this is particularly true in the case of silences generated during interactions with ill people. In this section, it is worth reiterating the point that Charmaz (2002) makes:

"Ill people intentionally remain silent when they believe that a) other people cannot comprehend their situations, b) their views would hurt a significant person, c) voicing them would prove too costly, and/ or d) no one wants to hear the story." (Charmaz 2002: 309)

There are, evidently, a variety of reasons why people may be silent in particular research interactions, and- of course- the reason(s) why somebody may be silent are ambiguous and subject to change. This idea is further demonstrated with reference to a quotation from an interview I conducted with Angela in which she explains that she is comfortable to talk to me about some things; but remains silent about other things:

*"I feel ok talking about this but there's other stuff that [pauses] I find shameful, but I shouldn't."*

Throughout all of the interviews conducted as part of the research, some issues were discussed whilst others were not. Taking a feminist approach that is sceptical of easy

categorisations means accepting that people's illness and disability experiences are not easily understood and categorised. Indeed, thinking about the sentence quoted from the interview with Angela demonstrates that experiences can never be fully understood. Instead our understandings of people's illness and disability experiences are much more partial.

To further explore this, it is interesting to reflect on one of the suggestions from Charmaz (2002) about why ill people may be silent during interactions (discussed in *Chapter 2*). Some people may not speak about their experiences of illnesses because they do not think others will understand (Charmaz 2002). For instance, if people live in constant pain, another person cannot actually experience the pain that is felt. As Scarry (1985: 13) argues, "to have pain is to have certainty; to hear about pain is to have doubt." Where there is this doubt, there is potential for people not to be believed or to be ignored. Given this, silences during interactions between researchers and participants reveal an important point about the way people with illnesses and/ or disabilities may feel or may be viewed by society. Feminist approaches encourage us to explore ambiguities and complexities in people's experiences and thus, as is evident here, highlight why silences might be important in illness and/ or disability narratives.

This point about the need to be sceptical of clear- cut categorisations has been hugely influential in this thesis. Alongside attending to issues of reflexivity, positionality and scepticism of clear- cut categorisations, the broader influence of feminist ideas is interwoven into the discussion presented throughout this thesis. Hence, whilst acknowledging that this thesis is not a heavily theoretical piece of research, my work is always underpinned by feminist ideas and practices. The value of such an approach has been briefly explored in this section, but- in the process of accounting for participants' experiences of negotiating multiple illnesses and/ or disabilities in subsequent chapters- this will become all the more evident.

## 3.2 Developing research aims

Consistent with this feminist approach to conducting research, the purpose of this section is to set out the aims of this research, as well as to present discussion of how these aims were formulated. This section will additionally seek to highlight some of the complications that have both forced and enabled me to reimagine those aims time and time again. Such difficult academic labour is rarely stressed in our writing (Barnes and Duncan 2013) but-in doing so-the complexity of the research process is underscored and our reasons to make particular claims to knowledge are placed in particular contexts.

It has been several years since I started this research. The project has changed in many ways over time- making it quite a different endeavour to that set out in my original 2010 proposal. Instead of just straight- forwardly setting out the aims of this research as I *now* see them at the end of the project, as part of a feminist commitment to acknowledging the processes of knowledge production, it is important to consider how the project has actually taken shape. Indeed, how and why did the questions addressed in this thesis come about? Whilst I now feel a sense of certainty about what this project is about for me (whilst realising that the project may have different meanings for research participants, supervisors and others), this has not always been the case.

To explore this, I have captured three points during the research process in which I articulated the (quite different) aims of the project, as follows (see next page):

**Point 1- January 2010**, The three aims stated in my research proposal for a) admission to the Geography Department at Durham University and b) Economic and Social Research Council (ESRC) funding:

- 1) To understand the experiences of place, such as the workplace, for people with MIH (mental ill health) in the North- East of England
- 2) Using this, to analyse the extent to which different environments can be linked to ideas of accessibility and disability for people with mental ill health
- 3) Within the N.E. of England, to consider ways in which the experiences of people with MIH can be improved in everyday places

**Point 2- May 2012**, The two aims stated in the end of 1<sup>st</sup> year presentation given in the Geography Department are to find out:

- 1) In which ways are different conditions positioned in terms of chronic illness and disability across time and space?
- 2) How do people with arthritis and OCD negotiate the changing categorisations of chronic illness and disability in their everyday lives and in relation to other identity categories (e.g. economic status, gender)

**Point 3- January 2015**, Aims articulated during the writing process

- 1) to explore and account for the ways in which negotiations of multiple illness and/ or disability experiences are felt, lived and responded to in various contexts (such as in clinical settings and imaginations of futures);
- 2) to examine some of the (emotional, social, economic, material, relational) implications of negotiating the (often) uncertain, confusing and incomprehensible bodily experiences associated with living with multiple illnesses and/ or disabilities;
- 3) to set out some of the problems and challenges that such multiply ill and disabled bodies present for the way our society currently operates (for example, in relation to expectations of bodies in workplaces and the organisation of public transport infrastructure).



A common theme across these stages of the research is an interest in the experiences of people living with mental ill health (MIH). This was initially manifest as a general interest in experiences in particular places (such as workplaces)- with the idea that specific environments might alleviate or exacerbate feelings of stress and depression (see Point 1, above). At that time I was particularly focusing on the literature written about 'therapeutic landscapes'. For example, Gesler *et al.* (2004) and Curtis *et al.* (2007) were interested in thinking about how hospital designs in the UK could be evaluated in terms of their therapeutic qualities. However, given that originality is used as one of the key barometers of academic quality (Guetzcow *et al.* 2004), my considerable thought about this concept of 'therapeutic landscapes' failed to yield much of an idea about how my research could contribute anything more to the existing work. It seemed reasonable at that early stage in my research to try and focus less on a particular concept and –instead- just to think about a broader range of ideas relating to the geographies of mental health and disability.

This desire to consider a broader range of ideas is reflected in the development of more 'open' aims, as detailed in the presentation I gave at the end of 1<sup>st</sup> year departmental conference (see Point 2). By that time I was interested in the politics of negotiating the labels of 'chronic illness' and 'disability' in relation to the particular conditions of obsessive compulsive disorder (OCD) and arthritis. Specifically, I wondered about the extent to which people with both of these conditions actually identified as living with either a chronic illness or a disability. To answer this question, I started to recruit people with OCD from a mental health resource centre in Durham.

After having a conversation with an academic in the geography department about my interest in people's experiences of multiple illnesses and/ or disabilities, I was encouraged to ask interview participants about their range of illness and/ or disability experiences. It quickly became clear to me that these experiences were hugely significant and that- far from being just one area that this research focuses on- it would be beneficial to build the whole PhD thesis around this idea. Hence, it was only after beginning the process of data generation that, an interesting and under-researched topic captured my imagination. Such a grounded theory approach has become quite commonplace amongst qualitative researchers (Bryant and Charmaz 2007), after the publication of Glaser and Strauss' (1967) book called 'The Discovery of Grounded Theory'. Their key argument was that grounded theory enables the formulation of theory based on data rather than simply to verify existing theories (Glaser and Strauss 1967). The most challenging aspect of taking a grounded theory approach lies in the necessity for the researcher to pay less attention to their own existing theories about their topic and- instead- to focus on the data (Urquhart 2013).

Although I recognise the value of pursuing a grounded theory approach, it also involved embracing a high degree of uncertainty about how the aims of the project might change. Indeed, a lot of time is spent simply hoping (Pandit 1995) that the project will generate interesting and original research. In turn, in this project, it meant having to demonstrate confidence and adaptability when presented with uncertain situations (Pandit 1995). In an interview with a member of staff at The Waddington Street Centre (my research site-discussed in the next section), I asked what she thought about the research process:

*"I think that obviously the research has changed quite a bit from we very first met and when you first talked about your ideas. Obviously you were originally looking at people with OCD and now it's sort of broadened across anxiety disorders in general.*

#### LATER IN THE INTERVIEW

*Some people really adapt to this environment and some people don't and that's just how it is. But you've just come in and been very comfortable. I think everybody feels very comfortable around you and so- therefore- that's helped in the sense that you've become somebody- you're not this sort of scary academic researcher who doesn't know anything about them and their lives"*

It was evident to this participant that the research had changed over time, but perhaps the extent of change was understood by her in terms of the groups of people I was interested in interviewing. Indeed, she noted that I was initially focused on OCD experiences before moving on to consider a range of anxiety experiences. Because I was deliberately open about the criteria for recruiting participants (see next section for more details), the degree of change in my research aims was perhaps not as visible to participants. This openness to change was a vital component of the research and- as I think is demonstrated in this thesis- has generated some interesting ideas.

This openness to change during the research process is certainly a feature of a grounded theory approach, but it is also consistent with the feminist epistemological framework on which the project is based. Although many feminists use a grounded theory approach to conducting qualitative research, some are resistant to parts of its underlying framework (Olesen 2007). Certainly, the idea that we can undertake research in which we ignore our personal histories and specific imaginations in an effort to approach our research as a 'blank slate' about the world is inconsistent with feminists' focus on the importance of reflecting on how knowledge is produced.

In that respect, it seems as though the initial imagination of grounded theory proposed by Glaser and Strauss' (1967) supports the possibility of "seeing everything from nowhere" (Harraway 1988: 571). Known as the 'god-trick', poststructuralist feminists are highly critical of the suggestions that social researchers can be detached, neutral observers of people's lives (Harraway 1988). Given this- a key feature of much feminist research is its intention to be reflexive about the positionality of the researchers despite it being difficult to do so in practice (Rose 1997). There is no end to the ways in which structures, norms and emotions impact on the research process:

"Attempts to reduce the practice of knowing to monadic conceptions of reason fail to grasp the complexity of the interaction between traditional assumptions, social norms, theoretical conceptions, disciplinary strictures, linguistic possibilities, emotional dispositions, and creative impositions in every act of cognition." (Hawkesworth 1989: 551)

Hence what we see is an apparent tension between the grounded theory approach that emphasises the 'blank slate approach' to research and feminism's focus on the importance of positionality and acknowledging people's history. However, I think one important commonality between feminist approaches and grounded theory approaches is the emphasis on the voices of participants in research. For example, feminism is highly sceptical of the uncritical authority afforded to theories about the world proposed by 'classic' accounts, with Hawkesworth noting that:

"The classic texts of Western history, philosophy, literature, religion, and science, riddled with misinformation about women, are handed down as sacred truths. When individual women attempt to challenge the adequacy of such misogynist accounts, they are frequently informed that their innate inabilities preclude their comprehension of these classic insights." (Hawkesworth 1989: 538).

Consistent with this, so too is grounded theory emphatic about the importance of listening to the perspectives and theories about the world that participants explain. Social scientists taking a grounded theory approach are not testing existing theory but actually developing new theory from data (Birks and Mills 2011). In that sense, the feminist and grounded theory pursuit of placing participants' ideas at the centre of research is really striking. Hence, the development of research aims in this project has been a constantly changing process, shaped by interactions with participants and others over several years. Rather than viewing point three as an 'arrival' point in which all of the aims have been finalised, it should be noted that these aims are consistent with the work of this thesis as it currently stands (discussed in the introduction of the thesis). But this process is never 'final' as aims are constantly (re)

packaged and presented in different ways to different audiences and in relation to discussion with others.

### 3.3 Research sites

At the beginning of the data generation stage of the research, I was interested in speaking to people living with OCD (obsessive compulsive disorder) about their life experiences. To address this aim, I approached a mental health resource centre in Durham City, North- East England, to ask if they would be interested in working with me to recruit participants from their centre. After a meeting with staff to present information about the project (including copies of my successful ethics review application from the Geography Department and a criminal record check), my proposal was put to board members of the Waddington Street centre who agreed that I could attempt to recruit participants from the centre. As a condition of this agreement, I was asked to use the name of the Waddington Street Centre in any research outputs, including presentations and published research. This condition will be further discussed later in the chapter in relation to issues of ethics.

There were several benefits of conducting research at this site. Firstly, and perhaps quite obviously, the purpose of the centre is to support people living with mental health problems so being in such a space afforded me the opportunity to meet several people who met the criteria for participating in the research. Secondly, staff members and service users were very supportive of me and of the research from the outset. For example, several staff members helped advertise my interest in conducting interviews with service users. Additionally, and in line with Davidson's (2003) suggestion about the need for support structures to be in place, I was confident that research participants could easily access help or services if any difficult issues arose during the interviews that they wanted to speak about outwith the context of participating in research. Finally, the Waddington Street Centre is located in the centre of Durham, so it was easy for me to frequently attend the site.

In order to provide more about the place in which the majority of data generation took place in this project, it is worth exploring more about the centre through both the use of available literature and through the voices of staff and service users. To begin with, the mission statement of the centre is to deliver:

“Effective Mental Health support through **LIFE SKILLS** and **OPPORTUNITIES**”  
(Waddington Street Centre 2014a) (original emphasis)

The Waddington Street Centre was first established in 1981 in response to the need for increased support for people with mental health problems (Waddington Street Centre 2014b). Members of Waddington Street United Reformed Church offered their hall as a base to provide this increased support from. The site was considered optimal because of its close proximity to the psychiatric hospital (which has since been relocated) and its central location in the city of Durham. For a person without mobility difficulties it takes just five minutes to walk to the centre from both the bus and railway stations.

The high demand for the service meant that the house next to the church was bought in 1988 and then a second (adjacent) house was bought in 1994 with funds from the health authority (Waddington Street Centre 2014b). By October 1998- and with funding from the National Lottery Charities Board- the houses were redeveloped to improve access, increase space (by building a new top floor) and provide an improved layout to meet the needs of the service. Once this new centre was completed, activities moved out of the Church Hall next door and into the Centre that is now open six days per week.

The Waddington Street Centre is a registered charity (number 2330506) whose operations are directed by a Board of Directors (Waddington Street Centre 2014b). In the year 2012/13, the charity had an income of just over £300,000 (Waddington Street Centre 2014c). Funding is provided by Durham County Council (41% from Children and Adults Services and 12% from The Supporting People Partnership), County Durham Primary Care Trust (16%) and The Northern Rock Foundation (11%), as well as other sources making up the remainder of the income (Waddington Street Centre 2014c).

Durham itself is a very small city in North- East England with a population of approximately 48,000 people (Durham County Council 2014). The county of Durham (of which Durham City is the largest settlement) has a population of 513, 200. More than three quarters of people in Durham County work in service industries and Durham City is the location of county council offices, a UK passport services office, a university and a hospital.

The Waddington Street Centre offers a range of learning and support opportunities to service users from County Durham. These include a partnership with New College Durham to run a range of courses every week including psychology, drama and music appreciation (Waddington Street Centre 2014a). Furthermore, a health trainer offers sports activities and health information, whilst a housing team offers accommodation support for service users. This is not an exhaustive list of support provided by the centre, rather an outline of the kinds of services offered.

As a member of staff (Maggie) explained to me, service users are referred to The Waddington Street Centre by social services staff. Although, in the past, people could drop-in to the Centre without a referral, the new system of referral is in place because:

*“We have to have someone to liaise with... when that person [service user] isn't well then... [we] can go to a social worker or a CPN (Community Psychiatric Nurse).”*

Maggie notes that this allows information about the history of the service user (where relevant) to be made available to staff at Waddington Street Centre in order to help ensure that the best support is provided by the service to the service user. It was noted in March 2013 that 109 people are registered to attend the service (Waddington Street Centre 2014b).

The Waddington Street Centre has adopted a social model of care. This ethos is described by Jen (a staff member) as beneficial within this particular context:

*“... we're a social model of care because... everybody who comes here has different sorts of care packages that they access. So obviously most people have clinical support, they'll have a consultant psychiatrist- they have a nurse that they'll see [and] they'll take some pretty hefty loads of medication to control the symptoms of their conditions. Obviously what we're trying to do is quite different to that. So we're trying to give people different options, we're trying to say that through- em- having access to social activities, through rebuilding your confidence and self- esteem and self- worth through doing meaningful activities that can have... therapeutic benefit. Actually by feeling part of something, by feeling you have a role, by feeling that you belong- that gives you a sense of wellbeing that we all need.”*

This approach to care was hugely valued by the research participants who voiced their thoughts about the service, as noted below:

- a) *“... I find Waddington Centre... it's a good help... and if it hadn't been for this place, - not just me- maybe a few more people... would be struggling day- to- day.” (Jack)*
- b) *“To me, 'safe' is somewhere... like Waddington Centre...” (Anna)*
- c) *“The staff are really comfortable to be around and caring. I like the staff here... here it's sort of getting us into activities, distractions really. That helps me as well- distraction.” (Patrick)*

These descriptions underscore the high regard that the research participants have for the Waddington Street Centre. It was in this context that most of the participants were recruited and then interviewed for this research. However, it is important to also note that some participants who came forward to participate in the research were not members of the Waddington Street Centre. Through ‘word of mouth’ the perspectives of a range of people

who live in the North- East of England were also important in this research. These interviews took place within Durham University buildings, mainly because of the ease with which I could book quiet and private locations that made them suitable for the process of data generation.

### 3.4 Recruitment of participants

My initial recruitment strategy was to talk to staff and service users about my interest in interviewing people who live with OCD. However, over a period between October 2012 and January 2013, this strategy proved to be quite unsuccessful. Although four people did agree to be interviewed, I wanted to generate more data from more people. At that stage, I decided to take two actions to meet this end. Firstly, the criterion for participating in the research was broadened to include people who experience any form of anxiety (including OCD, but also general anxiety disorder, post- traumatic stress disorder and agoraphobia, amongst others). Secondly, I was keen to build better relationships with a broader range of people at the centre so I offered to volunteer there for a few hours per week.

To focus on the first of these actions, an important consideration associated with broadening the scope of the research was that people who had already participated in the research might feel that the terms of the project have changed a lot from the initial basis on which they agreed to participate. However, on analysis of the data already generated, I realised that many were discussing their anxieties as manifest through OCD (alongside multiple illnesses and/ or disabilities). I also informally spoke to some of the initial participants about this change and they seemed very supportive. So in this sense, I am satisfied that people who originally participated on the basis that they were living with OCD are happy with the change made. Indeed, as shall be evident in the thesis, the common theme across the data is that all of the participants experience anxieties of some form alongside one or more other illnesses/ disabilities.

The second aspect of the amended recruitment strategy was to build relationships with a range of people at the Waddington Street Centre through becoming a volunteer. From January 2012 until August 2015, I worked as a volunteer at the centre's café on Thursday mornings. This job involved making tea and coffee and serving snacks, all the while chatting to the many service users and staff who use the space. Getting to know people helped to build trust, as a member of staff explained:

*“... by giving us extra time as a volunteer on top of your role as a researcher and- you know- people really do value that sort of thing because it makes them believe that you*

*actually want to be here rather than- without sounding too dramatic- rather than you're using them to get what you want... I think people feel that you've invested something of yourself into the organisation as well."* (Jen)

Further, although becoming a volunteer did help to increase recruitment to the project, it had many other benefits to both the research and to me, personally. Alongside helping to build trust, it also gave me the opportunity to informally discuss the progress of the research with people visiting the café. Indeed, the research project became a general topic of conversation, alongside discussing the many other things talked about in the cafe. Having the opportunity to volunteer at the centre also helped improve my own wellbeing by allowing me to get away from some of the stresses of PhD work (although volunteering, of course, presented its own challenges at times).

Returning to the issue of recruitment specifically, after volunteering for a few months, I arranged an information session in which people who were interested in the research could discuss the project and ask questions. Following the advice of the resource organiser (who later became the deputy manager) at the Waddington Street Centre (Ali Lee), I produced a poster to place around the centre to advertise the lunch time session (see Appendix A: Advertisement for research participants). The session had a turnout of seven people and I felt that it was quite productive in answering questions and concerns people had about the research. After that meeting, recruitment increased significantly and- by the end of the project- I had interviewed 20 people, including five members of staff/ volunteers. Within this group, three people did not attend Waddington Street Centre and were- instead- recruited through a snowball sampling strategy (as mentioned in the previous section).

When writing about research methodology it is usually advisable to provide a break-down of the characteristics of people who participated in the research. For example, the age, gender and race of participants are typically provided. However, because the name of the Waddington Street Centre is used in this research, this information will not be released in order to protect the anonymity of participants (as far as possible). This issue is discussed later in the chapter in relation to ethics.

Despite the success of the amended recruitment strategy, the process of recruitment was fraught with difficulty. A particularly pertinent issue in the context of conducting research within this field was the scheduling of interviews. Participants were frequently unable to attend arranged meetings due to either ill health or other commitments taking precedence. Some participants felt huge anxieties around using phones so, often I would not find out that a participant could not attend an interview until I arrived at Waddington Street Centre. This uncertainty sometimes made it difficult to conduct research but it also increased my



awareness of the uncertainties many participants faced in their lives. As was explained to me by a member of staff:

*“... due to the people we work with, you never know quite what to expect so you've always just got to be able to be flexible and- eh- work on the hoof really.” (Jen)*

Given this need to be flexible, every time I went to the centre, I brought interview materials with me so that I could conduct an interview if asked. Highlighting challenges such as these is an important part of being open about the processes of knowledge production in this research. Indeed, having difficulty recruiting participants is not unusual in research but- by providing this information- it is hopefully beginning to paint a more vivid picture of how the research was conducted.

### 3.5 Conducting interviews

In order to address this project's research aims, and in response to the complex nature of participants' experiences, I elected to undertake qualitative rather than quantitative research. Many feminist geographers use qualitative research methods in an effort to build trusting relationships with participants, hopefully reducing the sense in which people are objectified or 'mined' for data (McDowell 1996). Indeed, the ways in which quantitative data is gathered can sometimes be problematic. For example, historically, some geographical studies focused on the views and attitudes of the head of each household (typically assumed to be the male partner)- rather than considering how perspectives might be different amongst other people in the household (McDowell 1996). Using qualitative research methods allows more scope to listen to the detailed explanations and opinions that participants may provide.

Specifically, I chose to generate data through the use of semi- structured interviews. This method offers the potential to take a careful and compassionate approach to the conduct of research, in which people feel comfortable narrating life experiences (Valentine 2005). Conducting interviews does not involve collecting a 'representative' sample of experiences, but, rather, the aim is to focus on the individual experiences of participants (Valentine 2005). To generate this kind of data, a sensitive approach towards participants is necessary because of the likelihood that difficult topics will be discussed.

The interviews I conducted were semi- structured. This meant that I did not use a fixed set of detailed, pre- prepared questions (Valentine 2005). Rather, I brought a list of themes to each interview in order to prompt discussion (Valentine 2005). For example, I asked each participant about the themes of 'mobilities' and 'home' but encouraged very broad discussion

about these themes (See Appendix D: Interview schedule). This approach was beneficial because it provided some structure to discussion but also enabled participants to narrate detailed personal accounts of their experiences. As Saukko (2000) suggests in relation to conducting research with women experiencing anorexia, it is crucial to take participants' voices seriously in research, given the legacies of silence that have sought to devalue the experiences of some groups of people. Just as women with anorexia have been historically silenced because of their perceived inability for 'rational' thought (Saukko 2000); so too have the experiences of many people living with a range of illnesses and disabilities. Foregrounding the voices of participants through the use of semi-structured interviews challenges such silencing of particular groups of people and experiences.

However, it may be argued that the aims of this research could have been addressed through the use of a range of other qualitative methods. For example, Conradson (2005a) notes that focus groups can also generate information about participants' views and experiences. However, focus groups were not used to generate data for this PhD project because of the personal and sensitive nature of the topics I was interested in. Within a one-to-one interview setting I feel that some participants are more comfortable providing detailed descriptions of their experiences.

Another researcher undertaking a project on this topic may have opted to use ethnography or participant observation to generate data, particularly if volunteering at the site where many participants were recruited from. Using such research methods could have been beneficial as detailed insights would be gathered about people's lives over a long period of time. However, given that the name of the Waddington Street Centre would be provided in any research outputs (see section 3.6 for a discussion of the ethics around this), gathering this level of detail about individuals' lives may have compromised participant anonymity. In the context of this topic, I would also have concerns about how service-users and staff may have perceived me when volunteering if they thought I was gathering data about them at all times. Instead, volunteering helped to build trust with people in the centre, which helped with the recruitment of interview participants (discussed in the previous section).

There are also other methods that some researchers may have made use of to conduct research about this topic. For example, Parr (2007) writes about the potential of collaborative film making as a methodology to conduct research about the experiences of people with severe and enduring mental health problems. Additionally, there has been growing attention on the use of both arts-based and online methodologies in geography (Dwyer and Davies 2010). The decision to use semi-structured interviews in this research is a reflection of my familiarity with both the method and the benefits of its use, rather than any criticism of the

potential of these other qualitative methods. Indeed, future work on this topic may use some of these other methods to good effect.

With the use of any method, there are particular issues that become important in the process of generating research data. Within this project, there were several important methodological considerations germane to conducting semi-structured interviews with people negotiating multiple illnesses and/ or disabilities. Given the space limitations of this thesis, the three that will be discussed here are: power relations, belonging and anxiety. Providing this discussion is consistent with the feminist epistemological framework influencing this thesis, specifically in relation to the importance of issues of reflexivity and positionality (discussed in the first section of this chapter). Paying attention to the processes of knowledge production helps frame the empirical data discussed in subsequent chapters.

Firstly, the issue of power relations was significant in this project. Like any research project, researchers and participants constantly re-negotiate power relationships (Browne 2003). For instance, in this project, my request to record interviews with participants is situated within a broader mental health context in which recording devices are routinely used (Parr 1998). Given that many mental health workers record encounters with patients, the act of recording has become connected to patient-professional power relationships in which access to care and services are at stake (Parr 1998). Although I only recorded interviews after receiving written consent, it is important to note that seemingly innocuous acts such as these have the potential to shape power relations between researchers and participants.

Over the course of conducting interviews, there were several points at which I was concerned that these unequal power relations were problematic. For example, after conducting an interview with Jack, I wrote in my research diary that:

*“This participant suddenly left the interview room, after spending 20 minutes telling me about his life. When I met him in the corridor a few minutes later, he asked if he had done alright and if he had passed [as if was an exam]. I explained that it wasn’t an exam but that what he had said was very helpful to me and the project. I thanked him again for his participation.”*

After that I experience I felt very uneasy about the fact that this participant asked whether he ‘passed’. It did not seem as if he was joking, even though I explained the rationale of the project before beginning the interview. Reflection about this point leads me to consider the associations that the word ‘interview’ has with finding employment and receiving state benefits. Much like the case with using recording devices, asking to interview someone as part of a research project takes place in the much broader power-laden context of being interviewed to access work and services. Hence, although I attempted to emphasise the

points of commonality between myself and participants throughout the research, it is important to acknowledge that these power relations provide the framework in which the research data are generated.

Strongly related to this issue of negotiating power relations, is the idea of 'belonging'. As Dwyer and Buckle (2009) highlight, the status of the researcher as an 'insider' (who shares particular experiences or characteristics with participants) or an 'outsider' (who has different experiences or characteristics to participants) is of significance to relations with participants. This consideration seemed to be particularly pertinent after closely reflecting on one part of an interview with Michael. He explained that:

*"... you sit round a table with people who have the disability and I'll talk about it perfectly happily about it as a disability. But when it's in front of people who are not disabled you tend to hold back unless you're being asked questions [laughs and points to me] because it is- it's the embarrassment sometimes. Em and guilt- again... keeps coming back..."*

Michael laughed and pointed to me when he said that "you tend to hold back unless you're being asked questions". Given this, it seems that Michael does not think I live with a disability and- therefore- I do not belong to the same group as him. Within academic geography this binary is typically destabilised on the basis that similarities and differences between researchers and participants are much more complex (Dwyer and Buckle 2009). For example, even if I was considered as belonging to a particular group, this does not equate to a complete sense of sameness (Dwyer and Buckle 2009). This negotiation of insider- outsider status underscores belonging as both significant but also fragile. This was an important aspect of the research process and provides a further insight into some of the issues framing the generation of empirical data discussed in later chapters.

The third issue to highlight in this section about the process of conducting interviews is the significance of 'anxiety'. Indeed, all of the participants in this project lived with one or more forms of anxiety. These feelings of anxiety featured prominently not just as the subject of the interviews, but anxiety also structured the dynamics of the interview process. For example, this anxiety was evident at various points during an interview with Angela. She repeatedly reflects on her 'performance' during the interview with me, as the following quotation demonstrates:

*"...sorry, [laughs] am I babbling now?"*

*LATER IN THE INTERVIEW*

*...sorry, I hope this is alright.*

#### LATER IN THE INTERVIEW

*...oh my goodness I know I'm going to analyse this conversation for the rest of my life [laughs]- em- and say I was too open, I was too forward, I was- talked too much. Because I'm not usually this energetic and I don't usually talk this much and it's kind of thrown me a bit- em... it's an achievement. I've been out, I've did it, I've survived another day. But there's the anxiety over all the things that I've said and done and how I've looked and everything like that."*

Clearly, Angela was very anxious about participating in the research, and mentioned this quite a lot during the interview. It is important to be mindful of this because conducting research about anxiety necessarily means accepting that the research process itself is affected by it. Alongside issues of power and belonging, anxiety was one of three key methodological themes significant to the process of conducting interviews. Indeed, these considerations should always be recognised as the context in which empirical data was produced as part of this research.

### 3.6 Ethics

As has been referred to in several of the previous sections of this chapter, ethics was a key concern throughout the research process. Before beginning an interview, issues of consent were discussed with people interested in being interviewed. As well as providing information about what would be involved in participating in the research, I asked participants if they would like to discuss any aspect of the research (see Appendix B: Information for research participants). Each participant was asked to fill out a consent form in which they answered specific questions about whether they wanted to participate in the research and whether they agreed for the interview to be recorded (see Appendix C: Interview consent form). I emphasised that I would endeavour to maintain participant anonymity as much as possible but that the Waddington Street Centre would be used in any outputs produced.

As mention earlier in the chapter, using the name of the Waddington Street Centre in any research outputs was a condition of entry to the research site. This is completely

understandable because it could help the centre to attract funding, gain exposure and possibly even solidify its reputation as an organisation that is interested in ideas from research. However, this decision also presented me with an ethical dilemma. On the one hand I was keen for the organisation to benefit from the research in the ways described but I was also a little concerned that participants may be identified. Before conducting the interviews I emphasised that I would seek to ensure anonymity as far as is possible but I could not rule out someone guessing the identity of the participant, particularly as the name of the Waddington Street Centre would be used. Many of the participants seemed relaxed about this possibility.

In contemporary qualitative research, Tilley and Woodthorpe (2011) have described this issue of anonymity as very difficult to negotiate. Researchers are expected to communicate their research in a variety of ways, including (but certainly not limited to) the publication of peer reviewed articles and reports. Providing these outputs demonstrates to funders that they are getting value for money from research but it also makes ensuring participant anonymity more difficult (Tilley and Woodthorpe 2011).

In the context of this research, this issue of anonymity involves weighing up competing needs. This is particularly difficult in light of the changes to the aims of the project. When I initially approached The Waddington Street Centre I was interested in speaking to people who live with OCD. However, the project then changed to focus on the experiences of people living with multiple illnesses and/ or disabilities. As I write about participants' experiences I am very cautious about revealing the particular combination of illnesses and/ or disabilities that any one person experiences, as well as other identity characteristics (such as age and race) in addition to the fact that the research was mainly (though not wholly) conducted with people attending the Waddington Street Centre.

Indeed, I would identify the irreconcilability of this issue of anonymity as a key weakness of this research. Out of an abundance of caution, identifying characteristics of participants have been very sparingly provided in this thesis. There have been many instances in which I would like to provide a quotation from an interview but have felt that it may reveal too much detail about a participant's identity. This means that the depth of insight I would normally look to provide as a researcher is not present in some places. However, given the choice between trying to protect anonymity and providing very detailed descriptions of participants' lives, I have chosen to aspire to protect the anonymity of participants. Where this detail can be provided, it is. For example, several participants described living with back pain, anxiety and depression. This particular combination of illnesses and/ or disabilities was quite common so more detail has been provided about these experiences. Additionally, given that

this ethical issue is hugely significant to the research, I have been prompted to consider other ways in which it is possible to communicate key themes emerging from the research. As will be discussed more in the final section of this chapter, this includes the creation of pieces of ethnographic fiction. However, after discussing how data was generated for this project, I will first turn to explain the analysis stage of this research.

### 3.7 Analysis

“... in our zeal as qualitative researchers to gather data and make meaning, or to make easy sense, we often seek that voice which we can easily name, categorise, and respond to.” (Jackson and Mazzei 2008: 4)

Analysing qualitative data necessarily involves making decisions about how to understand the voices of participants. After recording interviews with 20 participants, I set about the transcription process. Each interview was transcribed *verbatim* and details about both language and tone were included in brackets within the text. Transcribed data was anonymised and securely stored in both electronic and paper formats. I then made use of the software program ‘Nvivo’ to code the transcripts. This software was very much used as a tool to search through data, spot key themes and identify potential relationships between ideas (Bazeley and Jackson 2013).

Essentially, the approach to analysis used in this research involved reading the transcripts, trying to understand what was said and then categorising data according to very broad themes. Some of these themes were: ‘risk and uncertainty’, ‘diagnosis’, ‘the future’ and ‘home’. Just as Kearns (1997) emphasises the importance of researchers becoming good listeners during the generation of qualitative data; so too must researchers be attentive readers when analysing this data. Closely listening to the voices of research participants opens up space for new theories and concepts to be developed (Kearns 1997). Similarly, a very close reading of the words of participants forms the basis on which particular knowledge claims are made.

Throughout this thesis, direct quotations from research participants are used to illustrate arguments made. It should be noted that paying attention to these ‘exact words’ does not negate the importance of the particular relationship dynamics that have shaped the ways in which this data was generated in the first place (Jackson and Mazzei 2008). Additionally, the very process of selecting quotations for use in this text involves making decisions about whose voices will be heard at particular places in the thesis. As Moss and Dyck (2003)

acknowledge, the quotations used in their research are selected on the basis of being particularly appropriate and useful in the process of making a broader series of arguments. Consistent with this approach, the particular quotations provided in this thesis have been selected to justify specific claims to knowledge.

Quotations are provided in italics throughout this text. Where appropriate, the specific exchange between the participant and me (as interviewer) is included. This helps to provide additional context to the reader, when necessary. In some of the extracts provided in the thesis I use the phrase 'LATER IN THE INTERVIEW' after an initial section of a participant's quotation. This convention is used to demonstrate that this topic was initially discussed in the interview (as quoted in the first part of the extract) and then returned to at a later point in the interview (as quoted in the next part of the extract). I also make use of ellipses (denoted as '...') quite frequently in order to highlight that words are missing from the quotation given. This is done to make quotations both easier to read and to allow a specific focus on the words relevant to a particular argument made in the thesis. Square brackets are also used in some places to provide additional information to the reader such as to explain colloquial terms used by participants or to highlight particular behaviours, such as laughing or crying.

### 3.8 Writing

After analysing the wealth of data generated during this research, I moved on to begin the process of writing. Within the discipline of geography, there has traditionally been little attention placed on this very important task (Barnes and Duncan 2013). But academics are all too aware of how difficult writing can be (Barnes and Duncan 2013). The idea that language is straight-forwardly linked to reality is simply not credible, considering there is neither a pre-defined reality nor an ability to easily express meaning through words (Barnes and Duncan 2013). Instead, writing produces and re-produces particular ideas and knowledges, rather than reflecting an objective, external reality (Barnes and Duncan 2013).

Indeed, the written work in this thesis is offered in the knowledge that participants' perspectives cannot be fully understood and ultimate truths cannot be reached. Embracing this theory of writing is reflected in several stylistic and substantive decisions made during the act of writing this thesis. Before explaining the structure of this thesis, three of these writing choices will be discussed in this section. These are: the integration of theoretical and empirical ideas, use of the first person narrative and the creation of pieces of ethnographic fiction.



Firstly, the writing style used in this thesis attempts to integrate academic and participant knowledge together. This means that participant voices and academic ideas are discussed together in many parts of the thesis. Consistent with feminist epistemological perspectives, it is important to both attempt to reduce power inequalities between researchers and participants as well as realising the value that participants' own knowledge has (Armstead 1995). The writing provided in this thesis does not aim to hierarchise different knowledges, but instead, to underscore the multiplicity of knowledge claims.

Indeed, this effort is also evident from the decision to make use of the first person narrative in written work. As Kearns (1997) explains, it is geographers who have built up close relationships with research participants who have embraced the use of the personal pronoun. For me, working with participants has meant acknowledging the multiple perspectives and relationships that are involved in conducting research. Indeed, the work written in this thesis is not the only or authoritative understanding of this project. I view particular ideas to be important, but participants may express different perspectives. To underscore my own positionality as just one voice in this research, I have made use of the first person narrative where appropriate. For stylistic reasons, I have varied the sentence structures used but always aim to make my own positionality visible within the research.

Thirdly, as part of an effort to provide alternatives to 'rational' and 'objective' academic writing styles (Inckle 2010), this thesis makes use of ethnographic fiction at the beginning of each of the four subsequent chapters. A key benefit of this writing methodology is the value placed on becoming creative by bringing together various pieces of data generated during the research process (Bruce 2014). In the four pieces of ethnographic fiction produced, I have attempted to use research data in an imaginative way to create stories that introduce and explain the importance of key ideas discussed in the remainder of each chapter. Taken as a whole any one story is not 'true', but rather it brings together key themes discussed by a number of people in the process of conducting interviews.

Specifically, in terms of the process of writing pieces of ethnographic fiction, there are several ways that any author could generate this type of work. For instance, some people may choose to take quite a systematic approach- in which any single piece of writing contains a particular proportion of direct (or only slightly amended) quotations taken from a particular number of participants. For me, within the context of this project, such an approach would lead to the production of some quite badly written pieces of work in which flow and plot are compromised. Instead, I chose to generate pieces of ethnographic fiction by firstly thinking about the character that I wanted to write about (each piece of ethnographic fiction

produced for this thesis focuses on the perspective of a 'fictional' character- Arran (Chapter 4), Kelly (Chapter 5), Hannah (Chapter 6) and Mark (Chapter 7)).

These characters are based on research participants that I spoke to, although no individual character is entirely based on a single participant. Using this character- based approach as my starting point, I reflected on the experiences that participants had narrated to me during the research and sought to weave these broad themes (as well as intricate details) into a storyline. For example, when I was developing the piece of ethnographic fiction used in Chapter 6 (entitled: 'Attending Waddington Street Centre: Hannah's experience'), I wanted to include examples of the many difficulties that participants have in being mobile. Hence, I wrote about this character's (Hannah's) experience with reference to the 'mix' of issues that research participants told me about, including: difficulties accessing toilets, needing to select a particular seat when using public transport and anxiety about leaving the house.

This creative approach to writing is particularly appealing because it enables ideas to be communicated in an interesting way. For example, these pieces of ethnographic fiction could be a potentially more interesting way of providing a basis to discuss research ideas with participants rather than providing an academic article. They also allow a significant level of detail to be provided which begins to communicate the prolonged and multiple natures of the issues faced by participants in this research. Unlike providing quotations, which often provides a particular example from a snapshot in time, use of ethnographic fiction enables more to be communicated about an array of aspects of life. Hence, the three writing choices discussed in this section are justified in the context of taking a feminist approach to conducting research about participants' negotiations of multiple illnesses and/ or disabilities. The style of writing presented in this thesis has the intention of communicating the multiplicity and complexity of participants' individual and collective perspectives.

Alongside discussion of other issues important to the research process- including the recruitment of participants, conduct of interviews, ethics and analysis- this chapter has sought to explore the rationale for the approach I have taken to this work. A key theme in this chapter has been the idea that decisions made about how to conduct this research are underpinned by a particular set of feminist ideas, methods and practices. At every stage during the research process I have endeavoured to reflect and respond to the difficult issues associated with conducting a project about a highly sensitive topic. However, as has been demonstrated over the course of this chapter, this process is often messy and challenging. Hence, my approach to writing about the research methodology of this chapter is rooted in an awareness of the difficulties and limitations of this project as well as an acknowledgement

that there are many other legitimate ways in which research about this topic could be conducted.

## Chapter 4: Incomprehensible bodies

### 4.1 A fictional interview with Arran

*Lindsay: Thank you for agreeing to participate in the research. So I guess I'm interested in what a typical day in your life might be like. Not that there is a 'typical' day but perhaps you could run through what kinds of things happen, what you do and so on.*

*Arran: Well, it depends. I'm not sure.*

*Lindsay: Maybe you could think about what you did yesterday?*

*Arran: Well, I was at Waddington yesterday. I try to come here twice a week but that doesn't always happen. Even yesterday it was a struggle to come in because I've been having trouble with my back and so I'm in pain all the time at the moment. It's like a cycle. When my back gets bad I don't get out to meet people and do things so I sit at home thinking bad thoughts. I try to occupy myself by watching T.V. but it's not the same as actually interacting with real people.*

*Lindsay: mmm*

*Arran: My wife is at home in the evening but I don't like moaning on to her all of the time. She must be sick of hearing about my problems. It's not fair on her. So yes, it is good to get out when I can but sometimes my back problems and mental health problems prevent me from doing things.*

*Lindsay: Right, so what kinds of things do you do at Waddington?*

*Arran: Well I quite like just chatting to the people who are here. I go to music appreciation sometimes but I find it quite difficult to stay in the one room for a long time. I need to get up and move around.*

*Lindsay: Oh right*

*Arran: Cause I don't like to be trapped in. My back might get worse or I could start to panic.*

*Lindsay: So when did you first start coming to Waddington Street Centre?*

*Arran: Oh eh I must have been coming here for about a year now. Although things have only really come to a head for me within the last couple of years, I do think I've had tendencies towards- sort of- emotional problems since I was a teenager. Sorry, am I going off topic?*

*Lindsay: No, no not at all. Please carry on.*

*Arran: So I think the first time I remember feeling really low was when I moved to a new school, aged 14. I moved to the new school even though it was far away from my house because I wanted to get away from the bullies at my old school. My parents had finally agreed to move me from that terrible old school.*

*I thought going to a new school would make things a lot better but then this group of other boys started targeting me. I don't know why really. At that time I remember suddenly realising that I was the problem, not my previous school and that it was probably going to be like that for my whole life. That thought just hit me so hard. I found it hard to concentrate on things and just kept thinking about what the point of any of it was- life, the universe, everything.*

*After that, things calmed down a bit at the school and I found a couple of other boys who I could hang around with. But that is the first time I can remember feeling really low. The depression was a bit on and off after that. When I finished school I managed to get quite a good job and I was happy for a couple of years but then I got made redundant. I was unemployed for a while after that. It was during that period of unemployment that I started getting back pain. I'm not sure what caused the pain and even now I don't have a particular diagnosis related to the back pain. I started watching TV all the time and just couldn't be bothered to do anything at all- even washing a few dishes was a task that seemed to take so much effort. So who knows why my back pain started but I know that at that time in my life I was pretty unhealthy and unhappy anyway- so that can't have helped and I do often wonder if I wouldn't have developed back pain if I had still been in work. If I had been in work then I would have been moving around more and that might have helped me.*

*Lindsay: And what did that mean for your search for work at that time? Were you able to work at all, given your back pain?*

*Arran: Well, I did try to find work but who wants to employ someone with back pain? I can't be sure whether I will be able to sit at a desk for any length of time or move around for any length of time. It is frustrating because even getting a desk job is difficult because I can't sit for long periods of time. Maybe they would let me sit for some time and then stand at other times. I don't see that working in long meetings though! What if I had to attend a two hour meeting? It is so awkward to continually have to get up off my chair when everyone is expecting you to remain seated. Even eating out at restaurants is difficult. I frequently make excuses to get up and walk around the restaurant. For example, I say I need the toilet, I say I've seen someone I know outside and want to speak to them or I say I need to ask the waiter something about my meal. I have many excuses ready!*

Lindsay: I see

Arran: *But I do think it's all such a vicious cycle. I'm in pain and then I get depressed. Also, even when I'm not in physical pain I still feel unhappy because I know that it won't be long until I'm in physical pain again. So basically although the physical pain is variable, the emotional pain is pretty permanent. Still, some days are better than others. I did have a really nice day out with a friend last week and I forgot all about my depression and back pain. It was just great but then I suddenly remembered about my health problems and I just came crashing down so quickly. Any limited happiness I get is short-lived.*

Lindsay: *Have you had any treatment for depression?*

Arran: *Well I have tried all the pills that there are but I don't actually think it's a question of 'treatment' for me. Everyone tries to say that you've got an illness but I don't really see it that way. I definitely see depression as real, even though a lot of other people do not but I don't think the way to sort it out is through taking medication. It's more about how you feel, how you were brought up and what your outlook is on life. There is no amount of medication that is going to make you naturally happy and optimistic. I also wonder why everyone is so obsessed about the need to be happy and optimistic. There are good reasons to be unhappy. You just need to watch the news to see why! I don't buy the idea that I am 'ill' because I'm unhappy. Depression does impose significant limitations on my life and it would be nice to be happier but I don't want to take any more pills. Coming to Waddington helps alongside developing hobbies and having support from family and friends.*

Lindsay: *yeh*

Arran: *I've started doing an upholstery course and I've found that really beneficial to my wellbeing. Although I can't always do the work because of my back, it gets me concentrating on something. I feel happy to be learning something new and think that it could potentially mean that I have a new area to get involved in. I've heard that some people work from home in their garages and are able to get quite a bit of work upholstering old bits of furniture. It also sounds quite nice to work for yourself because you could take a break whenever you need to. That is vital, given by bad back and mental health. Although I'm saying all this, I know that I never stick to anything and that I'm likely to fail at my course anyway. But we will see what happens.*

Lindsay: *you mentioned the importance of having support from family and friends. Do you feel that you have that support? Do you family and friends understand your back pain and depression?*

*Arran: Well it is hard for some of them to understand why someone who is relatively young has hardly worked in their life. It is also difficult for them to understand because the back pain and depression are both invisible. If anyone was to see me in the street they wouldn't think I had both of those problems- apart from the fact that my depression means I don't care about appearance that much. I often think that if I had a visible disability then people would understand why I have such difficulty with daily life. It also doesn't help that my back pain is not related to a particular diagnosis. I've had x- rays and all sorts of investigations but they can't find any reason for me being in this much pain. Sometimes it feels like people think you are making it all up.*

*But I don't really blame some of them for not understanding. I don't really understand it very well either! Sometimes I seem relatively alright but then an hour later I could be on the verge of action to commit suicide or rolling around on the ground in terrible pain begging the person answering my 999 call to send an ambulance immediately so I can get strong pain relief. I just feel that everything is foggy: I don't understand why I got back pain, I don't have a particular form of back pain diagnosed, I don't know when I will feel better or worse, I don't know what causes my body to act up and I certainly don't know the solution to these problems. All of this 'not knowing' means I am just in a permanent state of confusion, even though I am constantly trying everything to understand how to manage my conditions.*

*I also get annoyed with my next door neighbour who always makes a point of telling me how hard he is working and how many hours of overtime he has to do just to get by. He is always telling me that he is sick of people using the tax he contributes in order to pay benefits. He says this knowing full well that I don't work. It's not like I'm exactly having a party when he is at work though! I'm sure he speaks like that just to make me feel even worse about my situation and to make himself feel better. So I think it is difficult to understand and I don't understand it very well but I think people could do more to understand that people who are out of work because of illness and disability are not exactly living the high life.*

## 4.2 Living with incomprehension

“An underlying assumption in medicine is that health problems present as subjective symptoms accompanied by objective findings.” (Malterud 2000: 603)

What if, like Arran, your symptoms of back pain cannot be explained by the presence of a particular illness or disability? What if medicine fails to offer a diagnosis at all? What understandings can be reached and by whom? What can be done? ... And who even cares?

This 'fictional' account of Arran's experiences communicates the sense of incomprehension that often dominates the lives of people participating in this research. Whilst a key premise of biomedicine is the coupling together of subjective symptoms (provided by a patient) with objective conclusions (provided by a clinician) (Malterud 2000), the experiences of people participating in this research cannot be characterised in such a straight- forward way.

In this first empirical chapter of the thesis, this confusion in the lives and bodies of people living with multiple illnesses and/ or disabilities will be explored using quotations from research participants. This work will emphasise the limitations of biomedical approaches (that foreground logic, rationality and individuality- amongst others) in the lives of people negotiating multiple (and sometimes undiagnosable) illnesses and/ or disabilities. Given the pervasiveness and acceptability of biomedical discourse in western societies, bodies that challenge this norm- such as many of those participating in this research- are often criticised, isolated and devalued.

In the same way as people with disabilities are typically viewed as unwelcome reminders of the limitations of medicine and science (Wendell 1996), this chapter explores the 'otherness' experienced by those whose bodies cannot even be explained (because of the complex intersections of multiple illnesses and/ or disabilities, amongst other reasons), never mind effectively treated. This group of people- I argue- are often not even accepted occupants of spaces in which ill or disabled people might normally be present in- such as clinical settings. For example, writing about the education of medical students, Shapiro (2008) explains that the desire to control and cure patients means that trainees who cannot do so tend to detach themselves from those whose bodies are incomprehensible and incurable. This sense of distance and detachment from others is a common feature in the lives of people negotiating multiple illnesses and/ or disabilities. Consequently, as shall be demonstrated in the next section, living with (always) complex and (often) incomprehensible combinations of illnesses and/ or disabilities is characterised by a struggle to be heard and accepted.

### 4.3 Irrational, unbounded and unproductive bodies

The experiences of those participating in this research present a challenge to dominant biomedical narratives that expect bodies to be rational and contained. This section will explore three ways in which participants' sense of bodily incomprehensibility destabilise such norms. Firstly, the desire for bodies to 'make sense' and behave in predictable ways means



that bodies that deviate from these norms may be labelled as 'irrational' (Shapiro 2008). This focus on rationality, as shall be explained, is understood as a key method through which particular complex and incomprehensible bodily experiences are dismissed. Linked to this is the idea that bodies that *demonstrate* their 'unboundedness' in specific, 'unacceptable' ways (for example, by behaving 'incorrectly' in public spaces) challenge the perception that bodies are independent entities (Shapiro 2008). This 'lack' of boundedness is typically positioned as a problem that needs to be rectified. Such 'irrational' and 'uncontained' bodies are also inconsistent with the idealised societal figure of the healthy, productive worker contributing to the neo-liberal economy (Shapiro 2008). Experiencing these three bodily characteristics-irrationality, unboundedness and unproductivity- meant that participants in this research did not just live with incomprehension, they were acutely aware of the *unacceptability* of living with complex, multiple illnesses and/ or disabilities that cannot always be understood or managed.

Beginning with the issue of rationality, it will be argued that hierarchised conceptions of the extent of a person's rationality tend to privilege particular bodies, whilst devaluing others. Indeed, participants in this research who expressed a sense of confusion about their different bodily experiences are positioned at odds with prevailing biomedical narratives that highly value the pursuit (and achievement) of understandings and explanations (Crossley 2000). To illustrate this point, it is useful to refer to an exchange I had with Carolyn:

*Lindsay: "when did you first... think you had agoraphobia?"*

*Carolyn: oh it must be over 20 years.*

*Lindsay: was it in response to something in particular or did you just develop it, or?*

*Carolyn: Well I, I was first in hospital with depression when I was 19 and I was in and out of the psych [psychiatry] unit for about seven and a half years and it was while I was in hospital that I developed the agoraphobia for some reason.*

*Lindsay: right*

*Carolyn: and- em- and it did rather overtake my life."*

In this instance, Carolyn's account of her agoraphobia, alongside depression, is one in which a reason is not offered to explain its development. In contrast to other quotations that I have focused on for the purposes of this project, this quotation initially appears not to offer a

great deal of detail. Trying to seek out a reason for this 'absence' of detail, I considered Charmaz's (2002) work on why ill people would remain silent about their experiences (also discussed in *Chapter 2* of this thesis). She argued that people may be silent about their illness experiences if there is a perception that one or more of the following are true: others will not be able to understand your experiences, it may cause harm to others, disclosing details would have negative consequences for you or because others are not interested in this information (Charmaz 2002). Hence, there are many credible explanations for why Carolyn may have been silent about the development of agoraphobia. But can this lack of detail actually be perceived as a silence?

On reflection, it seems that it is not necessarily the case that Carolyn did not provide an account of the development of her agoraphobia whilst she was receiving treatment for depression. Although Carolyn may have been selective about the reasons given for the development of the illness (as we all are about disclosing various pieces of information about our lives), it is also possible that Carolyn simply did not know why she developed the condition and could not offer any further detail. Indeed, she notes that she developed agoraphobia for "some reason". This is perhaps indicative of a sense of confusion about what the particular reason might be. Significantly, this means that a 'rational' explanation is not provided.

However, the way I initially analysed this quotation is reflective of the dominant biomedical culture that we live within. Rather than immediately accepting the account provided by Carolyn, I wanted to seek out answers. This desire for rationality is a key pillar of biomedical thought that privileges rationality over irrationality (Crossley 2000). Within psychiatry, in particular, there is considerable emphasis on diagnosing and treating unacceptable, 'irrational' bodily experiences. As Crossley (2000) suggests, particular emotions have become 'colonised' by medical experts aiming to 'rectify' bodies that are deemed to be irrational. Consistent with this idea is that, as in the case of Carolyn, any bodily experiences deemed to be undesirable are typically situated as irrational.

For the purposes of this PhD research, one particularly important strand within this discussion about rationality is its strong association with credibility. Many participants in this research suggested that experiencing *multiple* illnesses and/ or disabilities resulted in the feeling that they were not believed- that having so many 'problems' was simply *incredible*. This stigma was noticeable from an off- the- cuff comment made by Stephanie during an interview. I was, fairly inarticulately, trying to ask a question about the future and how it related to her multiple illnesses and/ or disabilities. The exchange proceeded as follows:

*Lindsay: "... I suppose we talked about the future a bit. Like, how do you think- in relation to... OCD (obsessive compulsive disorder)*

*Stephanie: yeh*

*Lindsay: and depression*

*Stephanie: and all of the others [smirks and laughs]."*

As I was beginning to list the illnesses and/ or disabilities that Stephanie experiences, she interjects to make a joke about the fact that she lives with so many bodily differences. For me, this participant's use of self-deprecating humour is a reflection of the negativity typically associated with giving voice to a long list of diagnosed (and undiagnosed) illnesses and/ or disabilities. As the dialogue with Stephanie demonstrates, her use of the phrase "and all of the others" has the effect of curtailing the listing process I was going through. This curtailment epitomises the idea that the more illnesses and/ or disabilities you experience; the less credible (and less rational) your experiences are deemed.

Given that even listing combinations of illnesses and/ or disabilities is viewed in a pejorative way, what hope is there that people's experiences of multiple illnesses and/ or disabilities can be understood more holistically? As explained in the previous chapter, a key task of this thesis is to underscore the impossibility of isolating a particular illness and/ or disability within a body. However, as the experiences of Carolyn and Stephanie demonstrate, the prevalence of a biomedical discourse that privileges the isolation of symptoms in order to reach a diagnosis means that any 'irrational' bodily differences (such as having too many illnesses and/ or disabilities to be 'credible' or not knowing why you developed an illness or disability) are often devalued.

The incomprehensible experiences of people living with multiple illnesses and/ or disabilities are also devalued because of their 'unboundedness' as well as their 'irrationality'. Containing particular bodily experiences is a prerequisite for occupying particular places at particular times. Indeed, the interviews conducted with participants identify that their experiences of multiple illnesses and/ or disabilities sometimes lead to rejection and exclusion. For example, Daniel explains some of the difficulties associated with negotiating the visible symptoms of anxiety and panic, including sweating profusely, not being able to breathe or to find his way around a place (because of dizziness):

Daniel: "... if it was- say- a Friday night in a pub and you started getting anxious and stuff, I could imagine you getting thrown out. But if it was during the day... I think some people would see if you were ok, or whatever."

Daniel *imagines* that if his symptoms of anxiety and panic were to become visible on a Friday night in a pub then he would be asked to leave. Because the symptoms of anxiety and panic might typically be confused with symptoms of intoxication, particular places at particular times (such as a pub on a Friday night) may be difficult to negotiate. Hence, the containment of undesirable bodily differences becomes essential if access to particular places, at particular times is to be permitted.

An important aspect of the (above) quotation is the fact that Daniel is *imagining* how the demonstration of particular symptoms will be received by others in different spaces. So how has he arrived at this conclusion? The work of Shilling (2007) on body pedagogics is instructive here. He suggests that body pedagogics can be understood as:

"... referring to the central pedagogic *means* through which a culture seeks to transmit its main corporeal techniques, skills and dispositions, the embodied *experiences* associated with acquiring or failing to acquire those attributes, and the actual embodied *changes* resulting from this process." (Shilling 2007: 13)

Indeed, it is the process through which Daniel has come to learn how his body might be perceived in various circumstances that indicates how bodies are culturally reproduced and controlled over time. In this case, *the idea* that demonstrating particular symptoms is unacceptable in particular places is *learned*. However, this learning process is rarely attributable to a particular event or experience, but rather is a result of the ongoing and negotiated processes in which people learn how to navigate particular spaces, according to their life experiences and the experiences of others.

To understand more about the specific ways in which body pedagogics work, it is helpful to refer to the work of Lande (2007) who writes about the process of learning to breathe like a soldier. In his research with cadets in the United States Army's Reserve Officer Training Corp, it is shown that learning to breathe in the correct way is vital to participating in military activities- including running and the use weapons. In the case of running, breathing has to be done in a 'composed' way (Lande 2007). If breathing is too loud or not done according to the 'correct' rhythms (perhaps because a running activity is exhaustive and particular cadets will have lower levels of physical fitness than is expected) then this is considered

problematic (Lande 2007). This learning that bodies need to breathe in the 'correct' way is achieved through the use of humour, humiliation and the promise that breathing in a 'composed' way will help make you a good cadet (Lande 2007). Clearly, bodies do not just behave in particular ways; instead they *learn* to behave in particular ways in the context of a particular privileging of bodies that are correctly 'bounded' (for example by having 'composed' breathing).

Similarly, these body pedagogics shape the extent to which the behaviours of 'unbounded' bodies negotiating multiple illnesses and/ or disabilities are accepted or rejected in particular places. As the quotation (above) from Daniel demonstrates, he has learned that bodies that are visibly panicked and anxious in pubs on Friday nights may be subject to exclusion, even though he does not seem to have direct experience of this. Such body pedagogics not only result in the exclusion of people negotiating multiple illnesses and/ or disabilities from particular places and activities, but also the level of acceptance with which they are met in other spaces. Indeed, the site at which I recruited most research participants from was typically viewed as a broadly inclusive and safe environment- an environment where unbounded bodies were more accepted than in most public spaces. This is evident with reference to descriptions provided by a service- user (Anna) and a new volunteer (Emma) at the Waddington Street Centre:

a) *Anna: "To me 'safe' is somewhere- basically- like Waddington centre. I'm not going to be judged... But- I mean- even coming here, there's some days I feel paranoid. They don't really want anything to do with me, sort of thing. And I know it's all in my mind, sort of thing. But to me it's a real fear.*

*Lindsay: mm*

*Anna: you know, sort of. they're talking about me. They don't want to talk to me, you know? Different things like that- feeling like an outsider."*

b) *Emma: "...I don't like hospitals and I know what I'm talking about. But here, this place- it provides... a friendly and safe environment for them.*

*Lindsay: yeh*

*Emma: ... they're watched but without any pressure. This is what I like... they're not told what to do.*

*Lindsay: mm*

*Emma: they're not judged for their actions. Really, the volunteers or staff... have a very high understanding about mental health*

*Lindsay: mm*

*Emma: eh, because I saw- I've been around in many classes with people with mental health [problems] and sometimes they act really bizarre. But nobody tells them that that's not right..."*

In these quotations, participants explain that the Waddington Street Centre is a place where service users are not 'judged' (Anna) or 'told what to do' (Emma). Although Anna does explain that sometimes she feels paranoid that others might not like her, she still views The Waddington Street Centre as a place in which people with unusual bodily behaviours and experiences are welcome. Similarly, Emma notes that people whose bodies behave in 'bizarre' ways are never told that 'that's not right'. In this sense, the Waddington Street Centre challenges the dominant biomedical notion that problematic bodily behaviours need to be actively contained or bounded.

But it is important to underscore that this acceptance of the sometimes unbounded behaviours of people using the Waddington Street Centre takes place in the broader context of many other spaces excluding those people, as the quotation from Daniel (above) about the unacceptability of demonstrating panic and anxiety symptoms in a pub on a Friday night shows. Accessing such places where 'unbounded' bodies are welcome is highly contingent on factors including the structures of specific agencies, available support and financial resources, as explained by Hall (2005) in relation to his work with people with learning difficulties in Perth, Scotland. Indeed, although participants in his research did explain that there are some places in which 'unbounded' bodies were welcome; these sometimes existed *in spite of* the many spaces in which participants felt excluded (Hall 2005). Certainly, the 'irrational' and 'unbounded' experiences of those living with complex and unpredictable combinations of illnesses and/ or disabilities undermines dominant biomedical narratives about how bodies should act, but often this message is not heard in the context of the many structures and practices that marginalise and exclude those 'unacceptable' bodies.

One important structure and practice is that of *work*. In the third part of this section about

how the incomprehensible experiences of people living with multiple illnesses and/ or disabilities undermine dominant biomedical conceptions of bodies, it will be demonstrated that any variable and uncertain aspects of bodily symptoms, behaviours and experiences are inconsistent with the idealised societal figure of the healthy, productive worker contributing to the neo- liberal economy (Shapiro 2008). Of course, living with the sense of incomprehensibility associated with trying to negotiate combinations of complex illnesses and/ or disabilities means that a person's availability for work cannot always be guaranteed. Therein lays the issue. This idealisation of the 'productive' worker is epitomised by the current UK Government's approach towards people receiving illness and disability related benefits. As a member of staff at the Waddington Street Centre explained to me, the pressure to move people into work (and, therefore, become 'productive') is often inconsistent with *understanding* and *accepting* the incomprehensible and complex realities of living with a range of symptoms and diagnoses:

*Jen: "... there are always different agendas within social care so everybody comes here through social care. Now, because the big thing on the agenda at the moment is 'moving people on' and- particularly- moving people into employment, what we're seeing more of now is that people want a fast turn- around. So some [social care] teams are referring people in and within a year or sometimes two years, they basically want us to have made that person fully employable, gotten rid of their mental health problems completely and have them ready to move onto into- you know- at least part- time work and lead a normal... life. Now, that's because they then have a pressure on them from above because that's the government agenda- the government agenda is 'get people off benefits and back into work' and then obviously- you know- team managers say 'ok you need to kind of get people off your case load'. So we're seeing more and more people- em- who are being taken off case loads. So social workers are saying 'we've assessed you; we don't really think that you need a mental health service anymore because we think you're sort of alright- off you go'. Now the person's probably alright and has probably managed to sustain their wellbeing because they've been coming here regularly and it's through coming here and getting the support that they get through Waddington Street Centre which has actually kept them quite stable. We don't know because it hasn't happened yet but we can pretty much guarantee that as soon as these people aren't coming to Waddington Street and they're back to being isolated within their communities, and having very little human contact that obviously- you know- they'll become unwell again and we'll probably just see them referred kind of back in the other end of the cycle. It's like a revolving door thing. So, essentially what's quite frustrating for us now is that ,where people in the past were referred, and what we were about was about sustaining people's wellbeing... so it wasn't about presenting people with a magic cure or*

*'moving people on' because a lot of people who come to Waddington Street Centre are called 'severe, critical and enduring'. So- you know- they're at the far end of a mental health problem. Those people, you know, they're not necessarily going to be cured. It's always just going to be about managing their symptoms and coping in the best possible way that they can. Some people here are never going to be able to work again. You know, some people here have been out of work for 20+ years. Who is going to employ somebody with no skills, who hasn't worked for 20+ years? I mean there are people who have barely been out of work for a year or so who are finding it difficult to find employment. So essentially it's because the goal posts of kind of social care have changed...'*

From this detailed account it is clear that the 'moving on' agenda is an important way in which the privileging of 'productive' bodies is manifest in the lives of people with 'severe, critical and enduring' illnesses and/ or disabilities. Rather than accepting the variability of illnesses and/ or disabilities- which may improve, before getting worse- the focus on getting back to 'normal' is considered paramount. That version of normality is bound up with the imperative to become a productive member of society, regardless of individual life histories and experiences. The consequences of 'failing' to achieve this productivity are huge. Following the work of Vandekinderen *et al.* (2012) with disabled women attending a social workplace in Belgium, they describe the idea that 'unproductive' workers are considered 'waste' products. Significantly, this idea of being 'waste' to society is internalised, as a quotation from one participant in their research demonstrates:

"Look at me, nobody is missing me. I'm 40 and I never had friends. I never met people who showed interest in me. I've been married three times, and every time, they ran away, after they hit me and cheated on me. Why? I worked all day, I always looked after them and still, I'm the bad one. They say I'm the rotten apple in the basket. You would start to believe it ... I started working at the age of 14. I still have nothing. I'm still hungry. I'm still without money. I've always been beaten up. Why? [She cries] I'm burned out. I don't have the energy."  
(Traveller, 40 years old) cited in Vandekinderen *et al.* (2012: 711)

The problems that this participant has experienced in many aspects of her life make particular, expected forms of 'productivity' difficult. This 'failure' to be productive is at odds with a powerful discourse that privileges aspirations of productivity and- therefore- ultimately leads towards this woman feeling worthless. Hence, embedded alongside negotiating the bodily complexities that restrict abilities to become a 'productive' worker is the moral unacceptability of being 'unproductive', in the context of particular power structures that devalue such bodies (Vandekinderen *et al.* 2012)



This devaluation of 'unproductive' bodies can also be understood by thinking through the linkages between ideas of productivity and ideas of citizenship more closely. For example, Reeve (2009b) draws on Agamben's (2005) work to question conceptions about the perceived citizenship of people with disabilities who are unable to work. The association between disability status and citizenship status is imbued with politics about who is deemed 'disabled' and how we define 'citizenship'. Referring to Agamben's (2005) character of *homo sacer* (sacred man) as someone who "...may be killed and yet not sacrificed..." (Agamben 2005: 8) is helpful in extrapolating this politics. The difference between being 'sacrificed' as opposed to not being 'sacrificed' is determined through the perceived 'humanity' of a body (Agamben 2005: 8).

Considering this word in depth, just where does the threshold lie between 'humanity' and 'inhumanity'? For Agamben (2005), a central pillar of biopolitics is the idea that the threshold between inside and outside is constantly redefined and subject to change for particular political purposes (Agamben 1998). Crucially, who defines the threshold between illness and wellness, disability and ability? And what does it mean to be on the 'other' side of the threshold to that which is considered preferable, normal and acceptable? In the case of people living with multiple illnesses and/ or disabilities, I argue that the sense of incomprehension and variability of bodily differences mean that many are constantly negotiating a 'tight rope' in which the demonstration of particular bodily symptoms and behaviours needs to be managed across time and space.

These attempts at 'management' are important because occupying different spaces (at different times) requires varying degrees of demonstration and concealment of combinations of illnesses and/ or disabilities in order to be considered acceptable. Specifically in relation to productivity, the participants in this research typically found that expressing incomprehensible aspects of their bodies was unwelcome in both employment and government benefit claiming settings. These feelings of confusion about the acceptability of varying levels of productivity are shown in quotations from Kirsty (who is discussing the possibility of applying for jobs in the future) and Angela (who is discussing the prospect of attending an interview that will assess the extent of her entitlement to disability- related government benefits):

*a) Lindsay: ".and do you think about what the future's going to be like? and how OCD might impact you in the future? or do you stick to thinking day- by- day, or?"*

*Kirsty: Em, I do- pretty much- manage short- term. Em, but when I think about how I would manage in work, that really frightens me. Em, [I think about] whether I could cope part- time,*

*cope financially part- time as well, whether I could earn enough. And with other pressures and things. You know, if there was suddenly a big rush on for something... I couldn't compromise doing it properly for speed."*

*b) Lindsay: "often people do think [in terms of] 'physical disability' [rather than mental disability]... how do you think that works in terms of benefits changes? For example, to DLA [Disability Living Allowance] and things? Do you think that anxiety is understood within that?*

*Angela: from what I've heard, it's not really very understood. Em, it absolutely terrifies me because... I will go along to the interview [to claim benefits] and I'll either be having a good day (like this) or I'll be having a bad day. I'll probably be so anxious. Because, you see, I'm used to Waddington Street. I'm used to the people at Waddington Street. I feel safe here but my anxiety will go absolutely through the roof [at the interview to claim benefits]. Because I know somebody will be there judging me on what I can and can't do. Basically assessing me and not fully understanding the whole situation. Em, it's very difficult to understand the situation. It's taken my mam [several decades] to understand my situation fully. It's taken me [several decades] to understand it fully [laughs] I suppose... But it's the fact that it feels a bit degrading that I can't be trusted to say: "look, I really can't work." Em, I would like to be able to work. I would love to be able to work. Em, but filling a form in and saying everything that you can't do... and that- yes- my life really is this crappy... is incredibly demoralising. I understand why they have to do it, I suppose. But I don't think- necessarily- the best things are being put into place for the changes of the benefit systems."*

Both of these participants express their confusion about the degree to which others will be receptive to the incomprehension associated with their bodily experiences and its implications for productivity. In the case of Kirsty, she feels frightened about the *possibility* of not being able to cope in part- time work, particularly given the need to work at a pace that she may not be able to achieve. On the other side of the same coin, Angela feels that- particularly if she is interviewed on a 'bad' day- she will not be able to cope with the 'degrading' experience of being untrusted to state that she simply cannot work; rather she would have to explain every aspect of her life (even though she expects that this will not be fully understood by the interviewer) in order to show that she cannot conform to expected standards of 'productivity'.

Given this, both participants in this research could be understood to be caught between a rock and a hard place. *Uncertainty* about possible productivity levels coupled with uncertainty about whether other people will believe and accept these (sometimes uncertain)

levels of productivity mean that accessing *both* employment and government benefits become difficult. The experiences of both Kirsty and Angela effectively encapsulate the tension that those living with multiple illnesses and/ or disabilities negotiate on a daily basis. In the context of 'productivity' being privileged, uncertainty over whether others will believe and accept variability in bodily capacities (that may not be fully understood- such as is the case with Angela) results in the incomprehensible realities of participants bodies not 'fitting in' to either work or benefit claiming settings.

This sense that the bodies of people with complex and ambiguous combinations of illnesses and/ or disabilities simply do not '*fit in*' has been the common theme linking together the experiences of participants quoted in this section. Clearly, the incomprehensible, difficult to predict and understand bodies of these participants are inconsistent with biomedical narratives that, firstly, seek to make sense of and, secondly, contain any deviations from 'the norm'. As has been demonstrated, the 'irrational' and 'uncontained' bodies of people negotiating multiple illnesses and/ or disabilities not only destabilise the dominant biomedical model typically deployed to explain 'different' bodily experiences, but also undermine neoliberal assumptions about the link between productivity and morality.

Although this section certainly demonstrates the many ways in which the 'irrational', 'unbounded' and 'unproductive' bodies of participants in this research *undermine* dominant biomedical and neoliberal principles, it is also important to emphasise that these complex and incomprehensible bodily experiences are routinely devalued. Indeed, rather than acknowledging the challenge that the bodies of people with combinations of illnesses and/ or disabilities present to biomedicine and neoliberalism, the dominance of these structures is such that participants' bodily experiences are typically rendered 'unbelievable'. This hostility faced by people negotiating multiple illnesses and/ or disabilities is evident from almost every quotation presented in this section. Whilst it is difficult enough to negotiate complex and incomprehensible combinations of illnesses and/ or disabilities, the participants in this research are also acutely aware of the unacceptability of living with this incomprehensibility. However, as will be demonstrated in the next section, actually paying attention to this sense of incomprehension makes us aware of some alternative, (always) partial understandings of the bodies of people negotiating multiple illnesses and/ or disabilities.

## 4.4 Alternative understandings of bodies

“When chest pain can be reduced to a treatable acute lobar pneumonia, this biological reductionism is an enormous success. When chest pain is reduced to chronic coronary artery disease for which calcium blockers and nitroglycerine are prescribed, while the patient’s fear, the family’s frustration, the job conflict, the sexual impotence, and the financial crisis go undiagnosed and unaddressed, it is a failure.” (Kleinman 1988: 6)

The social implications of particular illness and disability experiences can be profound. Although the treatment of acute and curable conditions may not always be as straightforwardly successful as Kleinman (1988) suggests, the key point remains that there may be massive long-term social implications of living with illness or disability over a prolonged period of time. The participants in this research provide considerable detail about the ways in which social understandings of bodies can be used to narrate<sup>6</sup> their bodily experiences. Hence, whilst the previous section explained the ways in which the participants in this research undermined dominant narratives of biomedicine and neoliberalism, it is the purpose of this section to explore the (always) partial and relational social understandings of bodily differences that were articulated in this project.

Specifically, this section will explain the importance of wider identity negotiations in shaping the narration of participants’ bodily experiences. Just as this thesis explains the impossibility of isolating particular diagnoses or symptoms from broader experiences of negotiating multiple bodily differences; so too is it impossible to isolate these illness and disability negotiations from broader interdependent, social relationships within and between bodies. To illustrate this point, it is interesting to think about the links between gendered identities and health identities. For example, ‘Men’s Health’ magazine frequently links aspects of what is viewed to be good for health to the propagation of masculinity (Stibbe 2004). This includes promoting the building of muscles, eating red meat and watching television (Stibbe 2004). Clearly, this linking of specific gendered activities to particular discourses of health underscores the importance of the broader identity politics in which any illness or disability experiences take place.

With this in mind, this section will explore participants’ narrations of their complex and incomprehensible bodies with a view to situating these experiences in relation to other aspects of their lives. This will be achieved with reference to three ‘alternative’ understandings that participants provided for their ‘different’ bodies. These understandings

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<sup>6</sup> For a more detailed discussion of the conceptual dimensions of discussing participants narrations of their illnesses and/ or disabilities, please see Chapter 7.

have developed particularly in the context of not 'fitting in' to dominant biomedical discourses (discussed in the previous section of this chapter) and, consequently, demonstrate the importance of other aspects of identity in reaching partial understandings about their incomprehensible bodies. Specifically, such narrations of participants' ill and disabled bodies include: a) 'being weird', b) having that 'type of personality' and c) having a family history of particular types of 'troubles'.

The first of these understandings is that the development of bodily behaviours and experiences that are different to 'the norm' may relate to a particular person 'just being weird'. This explanation was offered by two participants in this research, prior to any medical treatment being sought:

a) *Maria: "I was crying every day and things were just getting out of control. Like, I was miserable all the time [be]cause I couldn't stop these things [OCD related behaviours] and I didn't understand what it was. I'd heard of OCD but I never thought that was me. I just thought I was being weird and no one in my family really understood."*

b) *Lindsay: So when did you first feel that you had anxieties? Was it [as] a child, or?*

*Anna: Yeh, I've always been an anxious person- right from childhood. For as long as I can remember, really. But I think I only realised that it was actually happening to me when I was starting in my teens- you know sort of 12/ 13 year old, and stuff like that. I would get onto service buses and have a panic attack. Luckily for me, it was only really mild but I would get- like- really hot and sweaty and feeling sick and, you know, I'd just want to get off there. But at the time I didn't know why it was happening to me. I just thought it was me, sort of being a bit daft. To be honest, I got myself through it [but] even going into shops and stuff, I was the same."*

Both of these participants express their uncertainty about what was 'happening to' them (to borrow the words from Anna) and both came to the conclusion that they were 'weird' or 'daft'. These ideas expressed by Maria and Anna *may be* considered as 'assaults on the identity' (Freund *et al.* 1999: 132), whereby illness is perceived as a threat to the understandings people have about their bodies and lives. Such identities- and challenges to identities are significant- but also difficult to pin down. For example, Narayan (2013) notes that although the labels of 'woman', 'feminist' or 'Indian' are important identities shaping her life, there is no certainty that these identities correlate with homogenised and specific experiences or meanings. Within each identity category, people understand and live in quite complex ways (Narayan 2013). In this sense, the development of bodily difference- as

experienced in Maria's and Anna's teen years- may have presented a challenge to the way they understood their lives (as 'normal' teenagers) but actually pinning down the meanings and experiences associated with this 'assault' is difficult to achieve.

However, an alternative to the suggestion that the onset of illness may be viewed as an 'assault on identity' (Freund *et al.* 1999) is the idea that particular, existing (sometimes problematic) aspects of identity are actually *reinforced*. Analysis of Maria's and Anna's experiences is significant because, in both cases, young women have explained the development of their bodily differences as arising because they were being 'weird/ daft'. This narrative could be understood as reflective of the dismissive attitude with which many young women are typically treated. In research published by the Young Women's Trust (2013), for example, 46% of young women did not know who they could trust and one in three felt that they are judged unfairly when they ask for help (based on a poll of 1067 women, aged 16-30 in England). Consequently, the narratives that Maria and Anna initially developed to explain their bodily differences (prior to seeking medical attention) are formed within a broader context in which young women's voices are routinely devalued. Hence, the suggestion that the bodies of Maria and Anna are 'weird' or 'daft' may reinforce existing (stereotypical) aspects of their own identities, rather than present an 'assault' (Freund *et al.* 1999) to those identities.

Furthermore, as young women it may have made more 'sense' to Anna and Maria to view their behaviours and experiences as 'weird' or 'daft' rather than to consider themselves as 'ill'. Indeed, as this chapter has shown, a central feature of the lives of participants in this research is that they live with considerable confusion about their bodily differences. This confusion is particularly evident, in the cases of Maria and Anna (provided above), from their statements that: 'things were just getting out of control' (Maria) and 'I didn't know why it was happening to me' (Anna). One important aspect of this confusion- I argue- is the idea that their bodily differences are inconsistent with 'normal' ideas about *who* develops illnesses. For example, younger people typically do not expect to develop chronic illness, as a participant in Charmaz (1983) research explains:

"...It is hard to accept chronic illness — maybe a person expects it at 65, but they don't at 49." (Charmaz 1983: 183)

It follows that Maria and Anna (as young women) may not expect to develop illness at such an early stage in their lives. Illness is typically associated with becoming older and any 'deviation' from that norm often does not make 'sense' to people. Hence, the sense of incomprehensibility associated with navigating understandings of complex bodily differences

is strongly embedded within broader identity politics. Specifically, the (re) production of illness and disability identities is tied to negotiations of broader identity understandings, negotiations and politics.

Through analysis of Anna's and Maria's experiences, the importance of gender and age has been emphasised, but it is also important to underscore that other aspects of identities shape the (re) production of understandings about bodies (including- but not limited to- race, class, sexuality and religious beliefs). As an alternative to biomedical understandings of bodily difference, the narrative that particular bodies are 'just weird' is reflective of broader life histories and experiences shaping the lives of people negotiating illness and disability identities.

A second narrative that was offered in this research focused on the idea that particular people have particular 'types' of personality that are associated with developing particular illnesses. Rather than being a random event, Kirsty explains that the development of OCD (as one of several illnesses she experiences) is somehow related to the type of personality that she has always had, even though she does not articulate exactly 'what changed' to mean that the behaviours associated with this personality became pathological:

*Kirsty: "I mean, I was always very careful. Like, my airing cupboard was always neatly folded and things. But when it became pathological it meant I couldn't put anything in the airing cupboard or take anything out of the airing cupboard. So the airing cupboard was perfect but I couldn't use it.*

*Lindsay: yeh*

*Kirsty: ... it just went from being manageable- 'I could do this', 'I can keep it tidy' to being 'I can't use it at all'. So, em- you know, and it's stopping you doing all sorts of things.*

*Lindsay: yeh."*

In the process of narrating her organising and tidying behaviours, Kirsty suggests that her personality type is associated with the development of OCD. Interestingly, she articulates the development of OCD behaviours in terms of 'becoming pathological'. This indicates that a boundary was crossed *from* the performance of particular tidying and organising behaviours being considered as part of her personality *to* the performance of such behaviours being associated with illness/ disability. The 'escalation' of particular aspects of Kirsty's behaviour means that actions that were once considered as part of her personality, become so

'extreme' that they are now considered as medical problems. Behaviours, when viewed through this medical lens, are considered as deviating from norms about how bodies should function and perform. But how rigid is this boundary between personality type and pathology?

Reflection on Kirsty's narration of the development of OCD prompts us to consider the tricky associations that have recently been made between particular personality types and particular illnesses. Whilst Kirsty makes a link between personality type and pathology type, recent social sciences research has challenged this idea. Pickersgill (2013), for example, charts the rise of the idea that personality disorders can be treated by clinicians. Central to this change was the Department of Health's involvement in the rewriting of the 1983 Mental Health Act of England and Wales (Pickersgill 2013). At that time the Department of Health made the decision to consider personality disorders as treatable, and this perspective was reflected in reports and reviews that were commissioned (Pickersgill 2013). But the extent to which this move was rooted in biomedicine was questioned.

Later in 1999, for instance, the home secretary announced that new units would be built to 'treat' people with 'Dangerous and Severe Personality Disorder (DSPD)' (Pickersgill 2013). But DSPD was an administrative category created by civil servants rather than a clinical diagnosis developed by psychiatrists (Pickersgill 2013). The formation of this category enabled individuals to be detained by the state at sites dedicated to their 'treatment'. At that time, there was considerable concern that the role of psychiatry was being redefined as being about public protection rather than clinical diagnosis and treatment (Pickersgill 2013). Hence, this boundary between personality and pathology that Kirsty discussed in her interview with me is constantly subject to redefinition, particularly as the role of biomedicine keeps expanding to include aspects of bodily difference that would have previously been perceived as aspects of individuals' personalities. There is, thus, a blurring of the lines between personality and illness/ disability, particularly in relation to particular illnesses and/ or disabilities such as OCD.

Premised on the idea that the achievement and maintenance of health is universally good (Metzl 2010), viewing particular forms of bodily difference through a biomedical lens offers a both advantages and disadvantages to those living with what may have previously been considered as aspects of their personalities. Just as troublesome labels previously directed at individuals may become less frequent; a new set of difficult labels may be imposed on this group of people (Finkler 2001). For example, receiving a diagnosis of 'passive- aggressive personality disorder' (PAPD) may legitimate particular aspects of individuals' personalities by



referring to their differences as a 'disorder'. But this process of medicalization has been controversial. For instance, Lane (2009) quotes part of the criteria for diagnosing PAPD, as described by the American Psychiatric Association:

"These people are ineffective both socially and occupationally because of their passive-resistant behavior. For example, because of their intentional inefficiency, job promotions are not offered to them. A housewife with the disorder may fail to do the laundry or to stock the kitchen with food because of procrastination and dawdling." (American Psychiatric Association 1987 pp356- 357, cited in Lane 2009)

The boundary between what is considered as part of someone's personality and what is considered as a symptom of an illness are blurred. Interestingly, moralised gender dynamics also become part of the criteria offered in seeking to categorise PAPD. In this example, procrastination and dawdling are positioned as problematic symptoms of a housewife's illness, rather than as an aspect of her personality.

This redrawing of the lines demarcating personality from illness enables 'problematic' behaviours to not only be diagnosed through a medical lens, but also treated in such a way. Once particular behaviours are viewed from a biomedical perspective, the imperative to solve the problem becomes greater than if such behaviours are viewed as an aspect of personality. Hence, whilst 'having a particular type of personality' was offered by Kirsty to account for her bodily difference, this is also placed in the context of the medicalisation of personality in ways that might be problematic. Hence, in the first section of this chapter I sought to show the ways in which participants in this research may be understood as 'incomprehensible' when thinking about their bodily experiences in terms of the dominant biomedical and neoliberal pillars of society. However, as this discussion shows, in the absence of 'fitting into' such narratives, people do offer alternative narratives to explain what may be considered as incomprehensible and unclear behaviours.

But, interestingly, this narrative that links personality to particular illnesses was also resisted by some participants in this research. Vicky, for example, is frustrated by people who she regards as confusing aspects of personality with being ill. She explains this in relation to the difference between OCD and OCPD:

*"I think there's massive confusion between OCD [obsessive compulsive disorder] and OCPD [obsessive compulsive personality disorder] and people thinking that by keeping their room really tidy they have OCD. But there's actually very little or no anxiety underpinning [it]."*

*And you try and explain to people 'you haven't got OCD'- not from a personal point of view but from 'this is the medical definition of OCD'... it's almost as if people think it's this really cool, alternative mental illness that is quite attractive to have. Cause when you try to tell them they've actually got a personality disorder, not an anxiety disorder they go: 'no no no'... which is just bewildering to someone who has it [OCD]."*

As is explained in the next chapter, it is also important to note that Vicky has not 'achieved' a diagnosis of OCD herself. Within this context, Vicky's demarcation between OCD (which she experiences) and OCPD (which others often confuse with OCD) could be perceived as a way in which it is possible to legitimise her own experience as relating to an illness/disability. In this sense, it is in Vicky's interests to (re) produce a boundary between people with OCD and OCPD; rather than to emphasise the links between particular personality types and particular symptoms of illness. Hence, whilst Kirsty seeks to explain the development of illness/disability by referring to her personality; Vicky distances herself from any sense that personality type and illness could explain her own behaviours. Nevertheless, given that both participants draw on the idea of personality in their interviews with me- it does underscore the important debate and resource that some participants use to explain their different bodily behaviours. This is a contentious issue, as has been explored, but one which was important to a number of participants in seeking to account for their incomprehensible bodies.

A third account of the bodily differences experienced by participants in this research was the idea of genetic inheritance. For example, Heather explains to me that the development of her illness can be linked to her mother. She explains:

*"... there's actually a connection with my mother as well. She's a bit of a cleaner, a bit of a fanatical cleaner herself. My mum had certain things she would say are important and [she would] instil them into us. But I've got siblings and it never impacted on them!"*

In this example Heather interestingly suggests that she could have learned particular cleaning behaviours from her mother- but notes that her siblings did not. Hence, she alludes to the idea that there is a familial link. Talking about such a familial link can serve several functions, as Callard *et al.* (2012) explain in their article about schizophrenia. Firstly, by linking into a family history of particular illnesses, disclosing such an illness and/ or disability may be more understandable and less shocking to other people. Secondly, it relocates the 'origins' of the illness away from the individual to the wider family. Thirdly, retrospectively diagnosing family members is understood as a way to unlock and understand the behaviours

of other family members: it is like solving a mystery (Callard *et al.* 2012).

Heather's narration of the development of illness foregrounds the family to explain her behaviour. It is notable that this takes place in the context of particular OCD behaviours being poorly understood within biomedicine. Indeed, as with the other two social understandings of illness and/ or disability discussed in this section of the chapter, 'incomprehensible' aspects of bodily difference are often positioned outwith a biomedical lens. But the prominence of the family in Heather's account of illness development can be understood as the medicalisation of kinship (Finkler 2001). The individual is not the only patient- rather the extended family becomes medicalised through processes that are used to narrate the development of illnesses and/ or disabilities (Finkler 2001). With the rise of technologies to establish genetic causes of bodily differences, this may mean that particular families are increasingly deemed 'good' or 'bad' on the basis of particular medical histories (McLaughlin 2015). Despite this, as one of several methods that participants in this research used to 'make sense' of bodies that are not easily understood, talk of having a family history of particular types of 'troubles' was deployed to offer partial explanations for particular illness and/ or disability experiences.

In this section of the chapter I have set out three ways in which participants in this research explained their multiple illness and/ or disability experiences. Although not exhaustive in terms of the many and various narrations offered by participants, talk of a) 'being weird', b) having that 'type of personality' and c) having a family history of particular types of 'troubles', helped some people to explain complex forms of bodily difference. But these social and pseudo- medical understandings of bodies were, significantly, narrated in the context of experiences frequently not fitting into mainstream medical and neoliberal thought.

It was in the third section of this chapter that I demonstrated some of the ways in which the bodies of people negotiating multiple illnesses and/ or disabilities are considered incomprehensible when thinking in terms of dominant biomedical thought. Specifically, the 'irrational', 'unbounded' and 'unproductive' aspects of living with a multiple ill and/ or disabled body are characteristics that are routinely devalued by our society. This chapter has shown that the incomprehensibility associated with negotiating multiple illnesses and/ or disabilities is unacceptable in many settings and contexts. The 'lack' of clear- cut medical explanations for people's complex forms of bodily differences is positioned as a problem in a society that feeds into and feeds off modes of thinking that privilege stability, rationality and productivity. Consequently, in this first empirical chapter of the thesis, I have explored an important

aspect of the lives of participants in this research- the unacceptability of living with an incomprehensible, multiply ill and/ or disabled body. This was shown through an exploration of both the ways in which participants in this research do not 'fit into' dominant ideas about the expected capacities and behaviours and bodies; but also in terms of the alternative narrations offered by participants in the context of biomedicine failing to explain their bodily differences. This chapter has also provided an opportunity to explore the various forms and implications of the incomprehensibility of people's experiences; something which is a useful starting point when reflecting on the lives of participants as they are further fleshed out in the remaining chapters of this thesis.

## Chapter 5: Diagnosis and treatment experiences

### 5.1 Going to see the doctor (again): Kelly's experience

#### **Before**

*The dizziness was just the latest in a long series of problems that I had experienced in recent years and it was getting to the stage whether I wondered if there was any point in consulting a doctor. So what if I have been feeling dizzy? I am getting old and these kinds of things are just part of the course. But this apathy about my deteriorating bodily capacities didn't sit well with my very assertive daughter-in-law who insisted that the NHS (National Health Service) must get involved. Not only had I made some albeit feeble attempts at dismissing her concerns, I'd initially denied that I was having any more problems than I normally had. Unfortunately though, I had made the mistake of losing my balance whilst trying to make a cup of tea. That was enough to get her straight on the phone to make an appointment to see the long-suffering GP.*

*In advance of the appointment my mind was running through how I would explain my presence at the surgery. Obviously I would have to speak about the incident involving the cup of tea, making sure to omit details that will take too long to explain in the short time slot provided. But it's quite hard to stick to 'the facts' during these appointments. I've grown so weary of trying to work out which specific symptoms might be relevant to making a diagnosis of yet another condition. For instance, at my last appointment I complained about not being able to get to sleep at night. The doctor said this 'insomnia' (another problem to add to the list) could be caused by any one of the ailments previously listed in my medical records. It has just become impossible to isolate any one of my existing (or new) symptoms to a particular illness category. So whilst I know that trying to mentally prepare for the next doctor's appointment is futile, I seem to get anxious in advance of the process. Clearly you have to wonder what the point is in wasting the doctor's time when I know she won't be able to work out what's causing the problem... and finding a solution would be as likely as winning the lottery.*

#### **During**

*I had only eaten the absolute minimum for breakfast. That was probably because I was both out of my usual routine and nervous about what the doctor would think about me. On the way to the surgery I began wondering how many times I had made this same journey*

*and- importantly- how many more times I would have to make the journey in the future. In some ways I was lucky in that at least I could still walk unaided into the surgery. Perhaps that would change in the future. I have watched so many of my friends decline- some of whom did so very suddenly. Even the familiarity of the unique smell encountered when walking into the surgery contributed to a sense that I was in a depressing routine that would only continue- getting worse- until death. The plastic plants made me laugh a bit though- did they really think this helped to create a better atmosphere?*

*My daughter- in- law had agreed to stay in the waiting room whilst I went into speak to the doctor. There was no need for her find out any more information about my various conditions than she had already amassed. Somehow she now seems to know about every aspect of my past and present bodily problems! I hate that I can't have complete medical confidentiality now because my problems have become so obvious to other people, with me even having to depend on others to do some things for me. The doctor was smiling as she came to collect me from the waiting room. It must be a front- surely she can't be the happy when listening to people's problems all day.*

*Dr Carson led me into the room and I took a seat. There always seems to be an awkward silence after we sit down. I'm not sure who should speak first- her or me? I begin by apologising for taking up her time again but say that my daughter- in- law made the appointment because I became dizzy whilst making a cup of tea, causing me to trip over the cat and spill the tea onto my right hand. Before I can say any more, the doctor starts asking me a series of questions: Have I felt dizzy at any other point? Am I eating at regular intervals? Am I taking all of the medication prescribed to me? I always try to follow the advice the doctor gives me but sometimes I feel like she is trying to blame me for some things. Heaven forbid I hadn't eaten my porridge on the morning I felt dizzy- clearly it would then be my own fault I burnt my hand on the tea. Anyway the chance of my daughter- in – law allowing me to regularly skip meals is slim to none!*

*The doctor then goes on to ask how I feel 'in myself'. But does she really want to hear or even have time to hear the honest answer? The truth is that I don't feel that I have much to live for now. I'm aged 74 and I've had my time. I worked as a teacher for many years and although the work was hard, it was rewarding. I used to be so involved in the community and I felt like I actually made a difference to the lives of the people I taught. Now I just sit at home all of the time. Large parts of the day are filled by watching awful programmes on the TV. Living with chronic pain means that I can't walk for far so I don't get out that much. I need to be ferried around to places by people who would rather be doing other things. The only*

*interesting things I can talk to other people about are set in the past- nothing good is going on in the present.*

*But I know the doctor can't really help with any of that so I just say to her that I am trying hard to get on with life. Despite this, the doctor suggests we might need a review of my care plan. She thinks it would be beneficial for me to attend a day centre a couple of days per week. I feel like I'm just in that transition stage between independence and complete dependence on others but I don't really have much choice in it so I agree with her suggestion. Anyway it might be good to get out and see other people. Additionally, the doctor says that she will book me in with the nurse to get blood drawn in the hope of finding out the cause of these dizzy spells. So that's yet another appointment to attend. I know there are no straight- forward solutions available so I just smile at the doctor as I walk out of her room.*

### **After**

*When we get home my daughter- in- law is keen to know what the doctor said. I just tell her that I've got an appointment to see the nurse next week for the blood test. In an effort to try and maintain some privacy I choose not to recount every second of the appointment. She would find it all out in the end anyway but it's good for her to know that I don't really want her interfering in my life. After my daughter- in- law leaves the house I decide it's time to crack open a bottle of (screw top) wine. It's only 11 o' clock but I don't really have much of a set routine anyway so I think it's fine. I've also learnt that it's best to get some enjoyment out of life whenever you can. It wouldn't be long until the next depressing instalment with a medical professional.*

## **5.2 Introduction: 'not fitting into' the dominant biomedical model of diagnosis and treatment**

Kelly's account of visiting her general practitioner (GP) raises several important issues that people living with multiple illnesses and/ or disabilities typically face when engaging with clinicians involved in their care. In this 'fictional' short- story, some of the difficulties associated with negotiating clinical encounters are set out, including, but not limited to: the inability to 'match' particular symptoms with particular diagnoses and treatments; feelings of repetition and exhaustion about the development of 'new' bodily problems in addition to existing diagnoses; and the idea that these issues will never be resolved. It is the purpose of

this empirical chapter to explore the first of these themes in more detail (the other issues are mentioned throughout this thesis, but given particular attention in *Chapter 7*).

Alongside the other empirical chapters in this thesis, it is argued that several important settings and contexts in the lives of participants in this research project (including mobilities settings and narratives of futures) are difficult to 'fit into'. Specifically in relation to the clinical settings discussed in this chapter, it will be demonstrated that the bodily experiences of people negotiating multiple illnesses and/ or disabilities present a challenge to dominant conceptions and practices of diagnosis and treatment. In clinical settings, the participants in this research go through processes of constantly (re) assessing the 'relevance' and 'importance' of particular symptoms in relation to the presence of 'other' symptoms and diagnoses. As the key offering of this chapter, these processes of (re) assessment will be explored with the intention of problematising the organisation of clinical settings that people negotiating multiple illnesses and/ or disabilities encounter.

This chapter is structured to examine issues of both diagnosis and treatment. Specific attention will be placed on the entanglements and ambiguities that participants face during these clinical encounters, including discussion of how these difficulties are understood and responded to by various individuals and groups of peoples. In the process of exploring diagnosis and treatment experiences, I am mindful of the importance of emphasising both the individual and collective nature of the themes discussed in people's accounts of clinical encounters. Following Davidson (2003), I approach each participant's experiences as highly personal but also potentially demonstrative of common themes evident across the interview transcripts. Hence, this chapter does not aim to be 'representative' of people's experiences, but rather to draw out particular theoretical points through the use of selected quotations from the interviews with participants (Moss and Dyck 2003). This selection process is, of course, 'uneven' (Moss and Dyck 2003) and based on what I view as important within the particular framework of the thesis.

Specifically, exploration of participants' diagnoses experiences is centred on discussion of three topics, whilst examination of treatment experiences is also organised into two topic areas (forming sections 5.3 and 5.4 of this chapter, respectively). These are:

**a) Diagnosis experiences**

- i) achieving diagnoses
- ii) contesting diagnoses
- iii) obscuring diagnoses



## **b) Treatment experiences**

- i) negotiating relevance and importance in treatment
- ii) treating one illness or disability to the detriment of another

Within each of these sections I explore how the experiences of people negotiating multiple illnesses and/ or disabilities disrupt dominant conceptions of the role and practice of diagnosis and treatment. This discussion presents a challenge to both those trying to negotiate clinical settings and those who are responsible for organising and providing medical services for such patients.

## **5.3 Diagnosis**

To begin with the first of these, 'achieving' singular (or multiple) diagnoses is contingent upon judgements made by medical professionals about the perceived relevance and importance of particular symptoms at any one point in time. In diagnosing patients, these judgement processes are understood as a key pillar of biomedicine that "legitimizes an ill body by naming a specific disease process and so permits access to particular modes of treatment" (Moss and Dyck 2003: 84). Bodily complaints unaccompanied by a specific diagnosis may be considered illegitimate, thus emphasising diagnosis as both a social and a medical process. Focusing on this issue of legitimacy, in the first part of this section I shall demonstrate some of the difficulties associated with negotiating multiple forms of bodily difference and- yet- never 'achieving' a diagnosis.

As an important aspect of this research, the negotiation of multiple illnesses and/ or disabilities sometimes takes place in the context of biomedicine 'failing' to 'match' particular forms of bodily difference with particular diagnoses. There are many reasons for this inconsistency, including the judgements of medical professionals about the perceived relevance and importance of initiating diagnostic processes. This point shall be evidenced with reference to one participant's experience of negotiating illness/ disability identities that have not been 'officially' diagnosed by medical professionals. As will be discussed in more detail in the next section about 'treatment', Vicky states that: "I sometimes refer to myself as having OCD and sometimes refer to myself as having an eating disorder." Vicky's experience involves complex and layered negotiations of the two illness identities she considers relevant to her: OCD and an eating disorder. Through reflection on this issue, we come to question the value and application of the dominant biomedical model of diagnosis to

the lives of people negotiating multiple illnesses and/ or disabilities. The following quotation from my interview with Vicky underscores some of the implications of 'failing' to diagnose multiply ill and disabled bodies:

*"I think that's really difficult as well, getting a diagnosis. I mean I've had maybe four or five- em- preliminary interviews or preliminary discussions with a new therapist who is going to pass me onto the next therapist, who'll pass me onto the right level of CBT [cognitive behavioural therapy]. And every single time I've said: 'can you please give me a diagnosis- yes or no?' Because, as someone who had a complex about attention seeking, the fact that no-one would tell me I was OCD was quite damaging and I think it's- I think it is so difficult to get a diagnosis cause everyone says: 'oh, I'm not qualified to give you a diagnosis' and it's like: 'well actually it would help my mental health if... you gave me to someone who could diagnose me'.*

*You having a diagnosis is not important in the grand scheme of things and I think that's really difficult and I think, I think as a sufferer I have a very personal idea of what OCD is, regardless of the medical definition and that is sort of an anxiety which leads you to develop a coping mechanism or an avoidance and that whether you class that as OCD or autism, that doesn't change the fact that you are doing these physical avoidance tactics to cope with anxiety and I think- I don't know- it just makes me really angry that, even if they'd turned round and said 'no you don't have OCD, you have this [another illness]' or 'we think you're an attention seeker'... it also diminishes it- it's like: 'oh so you've been diagnosed with OCD?' Well, no I haven't' because they won't diagnose me. It's really difficult.*

#### LATER IN THE INTERVIEW

*I don't think it's good enough and... I think if everyone I saw was not at a high enough level to diagnose me then either those people need to be trained and qualified to give a diagnosis or I should have been referred to a higher level up- whether that costs them an extra 60 quid or 200 quid or whatever. I think, I think it's not fair and I think if, because there is a lot of stuff now about how they're trying to raise the profile of OCD but actually all I can see- raising the profile of OCD is channel 4 programmes where obsessive cleaners go into obsessive hoarders' house and tidy up and I think we've got so many misconceptions. There's so many damaging portrayals of OCD out there... that I don't see how they can keep... not giving people a formal diagnosis. I just think it's unfair."*

Vicky's experience of multiple forms of bodily difference (OCD and eating disorder, alongside her references to autism and anxiety) have not been diagnosed and, thus, emphasise the limitations of current diagnostic practices. Vicky's frustration at not receiving

diagnoses, firstly, reveals the unequal power relationships at play between patients and professionals. Seeking diagnoses of the multiple forms of bodily difference that Vicky experiences was not a priority for medical professionals in any of the clinical encounters she recounted to me. This tension between medical professionals and patients underscores the bind that those with particular combinations and levels of symptoms sometimes face in clinical settings. Whilst it is necessary to achieve a diagnosis (or multiple diagnoses) in order to gain credibility (Moss and Dyck 2003), some patients are met with considerable obstacles in doing so. If the relevant medical professionals cannot be accessed or persuaded of the importance of diagnosis in clinical encounters, then it becomes difficult for patients to be viewed as credible in other contexts (such as explaining reasons for absence from the workplace).

Significantly, patients are not expected to be in a position of power within clinical settings. It is anticipated that patients will be passive- they will seek advice, take prescribed medicines and follow doctors' orders (Murphy 1990). But Vicky's experience of not being able to achieve diagnoses highlights the flaws with this conception of the relationship between medical professionals and patients in diagnostic settings. Those negotiating multiple illnesses and/ or disabilities are sometimes not able to have their multiple forms of bodily difference diagnosed in the context of the current organisation of clinical settings. Indeed, reflection on Vicky's account underscores the difficult experiences that some people living with multiple illnesses and/ or disabilities have in accessing diagnosis services.

The implications of this lack of access are significant for Vicky, given the dominant role of biomedicine in distinguishing between socially 'acceptable' and 'unacceptable' bodily experiences in our society. In Vicky's case, the failure to diagnose her symptoms meant that she was concerned that people would think she is just an 'attention- seeker'. Thinking through this idea in more depth, we can relate Vicky's feelings of stigma to the existing literature on the topic within the social sciences. Specifically, there has been considerable attention placed upon the stigmatising effect of being diagnosed with particular illnesses, including HIV/ AIDS. For example, White and Carr's (2005) study in Jamaica shows that stigma about both HIV and homosexuality has resulted in low levels of HIV testing, as well as low levels of access to treatment and care services. Similarly, interviews with Black African people in the UK highlighted some people's concerns about the extent to which people with HIV are welcomed within churches (Ridge *et al.* 2008). This (re) production of stigma takes place in the context of an HIV diagnosis being judged by some people as a product of deviant behaviour, either or both in terms of decision-making about sex or addiction to substances (Sontag 1989). The association of a particular diagnosis (such as HIV) with stigma has been well documented within the social sciences.

As an interesting contribution to the existing body of literature focusing on stigma, Vicky's concern about being accused of 'attention-seeking' also points to the stigmatisation of people who have not received a diagnosis or explanation of their symptoms. If symptoms have not been diagnosed, this often means that patients are met with doubt about the credibility of any claims to illness or disability. In Nettleton's (2006) research about the experiences of neurology outpatients in England who have medically unexplained symptoms (MUS), this issue is discussed at length. She argued that the experiences of her research participants were characterised by a sense of moral concern, chaos and ambivalence about the 'lack' of an explanation for their symptoms (Nettleton 2006). She explains this succinctly in her concluding point, as follows:

"In an uncertain context the pressure of constantly having to account for oneself and remake one's identity can be relentless and unsettling. Having to be seen to be 'reflexively' making an effort to find solutions and restore physical and social coherence can be as intolerable as the symptoms themselves. One is not allowed to be anomalously 'ill'. Society does not readily give people permission to be ill in the absence of an 'accepted' abnormal pathology or physiology." (Nettleton 2006: 1176)

The situation that Nettleton (2006) describes is one which Vicky seems to be referring to when she discusses her concern about being labelled as an 'attention-seeker'. The power of biomedical discourse is such that people with symptoms that either cannot be *or* have not been neatly explained are subject to suspicion.

As is evident from Vicky's experience, the fact that her symptoms had not been medically explained (even though she notes that an explanation could be provided if she was allowed to see an appropriately qualified professional) resulted in an expression of uncertainty over exactly what diagnoses are the most applicable to her bodily experiences. This was problematic for Vicky because going through the process of achieving a diagnosis is an important method through which symptoms become accepted or rejected by society. When a diagnosis is not achieved, as in Vicky's case, there is a difficulty in understanding and explaining bodily differences. Unfortunately, just as professionals have placed little importance on diagnosing Vicky's symptoms; so too has Vicky questioned the extent to which other people will (consequently) view her symptoms as important.

But Vicky's experience also highlights the need to access the 'correct' clinical setting in order to achieve diagnoses. In the context of Vicky not being referred to a person qualified to make a diagnosis (or diagnoses), her body is disciplined to discuss 'relevant issues in the

relevant clinical context'. Of course, this heavily power-laden disciplining process is linked to the fragmentation of roles within medicine and the associated economic impacts of attending consultations with differently salaried professionals. Specialisation is a key component of the division of labour within our capitalist system that allows the dividing up of knowledge and expertise (Nancarrow and Borthwick 2005). Hence, access to a patient's desired service (for example, requesting a diagnosis) is always contingent on the roles and responsibilities of the staff member encountered in any one clinical setting.

Being 'matched' to the correct clinical professional in the correct setting is controlled by various gate keepers that assess the 'relevance' and 'importance' of accessing further clinical settings, including diagnostic settings. This is problematic in Vicky's case because there is no available setting for her in which to be listened to by an appropriately qualified professional and within which a medical explanation might (potentially) be reached. Not only has this negatively impacted Vicky's ability to access appropriate treatment as she does not have a diagnosis of singular or multiple illnesses or disabilities (as will be discussed later in the chapter), but it is also hugely disempowering. In disciplining bodies to discuss particular aspects of bodily symptoms in particular spaces, at particular times and with particular professionals but yet at the same time limiting access to those spaces, individuals with multiple and unexplained symptoms experience unnecessary difficulties in diagnoses. Unfortunately, in the case of those with potentially one or more unexplained illnesses or disabilities, this insistence on only discussing 'relevant' issues in 'relevant' spaces silences those who are afforded no spaces in which a diagnosis can be discussed.

This discussion about the 'failure' of research participants to 'achieve a diagnosis' serves to unpack the ways in which those negotiating multiple illnesses and/ or disabilities do not always 'fit into' existing clinical settings. Reflection on Vicky's experience shows that the disciplining of patients to discuss 'relevant issues in the relevant clinical contexts' can result in some people with multiple, undiagnosed illnesses and disabilities being neglected by medics. Participants, such as Vicky, cannot access particular clinical settings and are, thus, left feeling as though there is 'no space' where their bodies are welcome. This organisation of clinical space feeds into and feeds off the stigmatisation of such undiagnosed, multiply ill and disabled bodies, as Vicky's fear about being accused of 'just being an attention- seeker' demonstrates.

Building on this work, the second strand of discussion presented in this section focuses on research participants' experiences of contesting diagnoses. Whilst Vicky's experience demonstrated some of the problems associated with the organisation of clinical spaces for people who have not achieved diagnoses, there were also several participants in this

research who 'received' diagnoses that they did not agree with. In a situation where a person understands their own diagnosis as different to how others understand the diagnosis, this leads to what has been described as "contested illness" (Moss and Teghtsoonian 2008: 7). Contested illnesses are rejected by others- including health professionals and employers- on the basis that it is inconsistent with current, pervasive knowledge frameworks about illness and disability (Moss and Teghtsoonian 2008). An example of this contestation is provided by James, who is negotiating multiple illness and disability identities whilst trying to continue his education:

*"... So I went to [a service in the North- East of England]. There, a psychologist and his, sort of, student friend sat me down for an hour and a half asking me quite probing questions. And... he said: "I'm not convinced that you have obsessive compulsive. I'm convinced that you've got mild autism and intimacy issues." At the point where you've had it for [several] years, it's quite a bewildering thing to think about. I didn't really believe him but it was the only way onto my course so I had accept that that's what they think I have. So, even now, I think that [name of educational establishment in N.E. England] sees me as a person that has autism- not obsessive compulsive. [But...] I think I know what I have!"*

#### LATER IN THE INTERVIEW

*"... to be accepted onto this course again I had to go through a lot of channels. I think it was... student finance England and the [name of educational establishment] that wouldn't let me on [to the course] unless I had medical evidence that... I was suffering from obsessive compulsive. A year's worth of counselling wasn't enough..."*

James is negotiating multiple illness and disability identities. Whilst he perceives his bodily experience as relating to OCD, his psychologist perceives James to be experiencing autism and mild intimacy issues. This contestation is important because it is fundamentally about the narration of accepted and rejected identities. As Somers (1994: 631) argues: "struggles over narrations are thus struggles over identity." Whilst James identifies as living with OCD, he also contends with what he views as erroneous identities imposed on him by other people. Such an incapacity to fit into the acceptable range of available identity narratives can sometimes lead to feelings of confusion, powerlessness and anger (Somers 1994). The rejection of James' illness identity by his psychologist underscores diagnostic processes as heavily power-laden, and sometimes particularly difficult experiences for people negotiating multiple illnesses and/ or disabilities.

Significantly, this difficulty also extends outside of clinical settings. The power of the medical establishment is such that patients' perspectives on the nature of their illnesses and disabilities are not valued in other contexts (such as education and employment settings), if there is a deviation from the perspective of clinicians. James explained that, in order to get accepted onto his course again, he needed to provide medical evidence to justify his initial leave of absence. In trying to attain this medical evidence he had to go through an unwanted meeting with a psychologist that resulted in him being diagnosed with mild autism and intimacy issues. Given the power inequality between medics' opinions and patients' opinion, James had to accept the perspective of medics in order to continue with his education. Clearly, spaces of diagnosis can also be spaces of contestation for patients and doctors trying to categorise multiply ill and disabled bodies. But, as James' experience shows, negotiating multiple illness and disabilities takes place in a context where the perspectives of patients are less powerful than those of clinicians and this, in turn, feeds into a wider devaluation of individuals' perspectives about their illnesses and disabilities in other spaces, such as those of work or education.

In this power-laden context, it seems that James' experience of contested diagnoses is an example of "epistemic violence" (Spivak 1988: 280). This is described by Spivak (1988) (with reference to imperialism) as: the suppression and dismissal of the knowledge of particular groups of people on the basis that it is deemed irrational, unscientific or incomplete by members of more powerful groups. This is not to say that any one person necessarily intends to silence this knowledge (Dotson 2011), but historical (and contemporary) institutional power inequalities create spaces for some people to be heard and others to be silenced. The ability to (re) produce or deny 'acceptable' health narratives underscores the privileged position that medical professionals occupy as well as the consequences this can have for patients contesting dominant knowledge paradigms. Hence, those contesting multiple illness and disability identities sometimes do not fit into the accepted model of diagnosis in which patients straight- forwardly accept the perspective of clinicians.

But the engrained power of medical diagnosis meant that James had to tacitly accept the opinion of his psychologist in order to continue his education. It follows that receiving a diagnosis of 'autism and intimacy issues' rather than 'OCD' might have implications for the adjustments and accommodations made for James outwith clinical settings (although he did not discuss these in the interview with me). The dominance of medicine in permitting and restricting particular organisations of resources in educational settings means that contested diagnoses are often neglected. The lack of space offered to those with contested diagnoses is evident on consideration of the student support offered to those with illnesses and/ or

disabilities at my own university. Durham University's Service for Students with Disabilities (DUSSD) states that:

“Upon provision of appropriate medical or psychological diagnostic evidence, and after consultation with an adviser, we can offer support to students who are experiencing difficulty as a result of a recognised disability, specific learning difference (SpLD), mental health problem or medical condition.” (Durham University 2014: online)

This statement's inclusion of the words: 'appropriate' and 'recognised' is reflective of the power of medical and educational establishments to make decisions about the legitimacy of any claims to illness or disability, including an assessment of which resources (for example, the provision of I.T. equipment to assist with learning) are allocated to accommodate people living with illnesses and/ or disabilities. Certainly, those providing their own thoughts about their diagnoses to educators will not be given much weight: the only 'legitimate' proof of the existence of illnesses and disabilities has to come via medical professionals

I argue that this could affect the sense of inclusion that people with negotiating multiple, contested illnesses and disabilities feel in educational contexts. We already know that some university students with disabilities do not feel understood at university. This point is clear from Mullins and Preyde's (2013) research about the experiences of Canadian students with invisible disabilities. They found that some students were reluctant to disclose their disability because they felt that others would not understand them (Mullins and Preyde 2013). Given this lack of understanding, it is unsurprising that those with contested diagnoses may also feel voiceless in educational settings. Indeed, how is it possible to voice this contestation in an environment where there is both a high level of authority placed on the perspectives of medics *and* a lack of understanding about any form of illness or disability experience (even if it is uncontested)? Hence, contesting diagnoses not only has implications for the negotiation of identities; but also in terms of the accessibility of clinical (and other) settings. Thus, the dominance of the current model of diagnosis that affords 'no space' for contestation is a significant problem facing some people negotiating multiple illnesses and/ or disabilities.

As well as contesting particular diagnoses made by professionals, some research participants resisted the entire medical framework that health and care practitioners had used to explain any bodily differences that deviated from the societal norm. Previous research conducted by Watson (2002) with 28 'disabled people' recruited through organisations for disabled people in the U.K. actually concluded that many participants did not see themselves as disabled. Instead, they rejected the problematic dichotomy between 'normal' and 'disabled' bodies (Watson 2002). It therefore seems that there may be differences in the way individuals and 'others' perceive illness and disability identities.



Similarly, some participants in my research sought to contest medicalised explanations of their bodily differences. This contestation is evident from my discussion with Jack, in which I asked:

*Lindsay: "So, you identify as having anxieties. [Are] there any other conditions [that you have]?"*

*Jack: for me, it's not a case of 'illnesses'*

*Lindsay: Yes*

*Jack: It's just- I've been, sort of, a lonely person-*

*Lindsay: right*

*Jack: -all my life. And I keep thinking [that] I've only achieved things here [referring to Waddington Street Centre] and I haven't achieved any goals outside, really."*

Although some people view loneliness as a health issue (see Tannenbaum *et al.* 2003), it is clear that Jack makes a distinction between illness and loneliness. To be referred to Waddington Street Centre, some form of diagnosis or information from a health professional needs to be provided. So in order to attend Waddington Street Centre, Jack would be diagnosed with mental health problems in addition to the 'physical' disabilities he later explained to me in the interview (though information about the exact nature of these 'physical' illnesses and disabilities is omitted here in order to protect participant anonymity). The fact that Jack does not think that he has mental health problems, highlights a resistance to medical explanations for what he views as 'loneliness'.

Looking to other literature on this topic is instructive here. Indeed, there is considerable cause to resist commonly believed medical knowledge about bodies. Specifically, I will provide two examples from the literature that destabilise this idea that any bodily differences that deviate from the societal norm could and should be understood through a medical framework. Firstly, Davis' (2010) research about OCD highlights why the dominant medical explanation of OCD is problematic. The narrative that OCD is caused by faulty neurotransmitters, an explanation also known as the 'broken brain model', assumes the condition is universal and unchanging (Davis 2010). But, problematically, there is a blurred boundary between those obsessive behaviours that are viewed as an acceptable part of culture and other behaviours that may be diagnosed as part of a medical disorder (Davis

2010). Thus, as cultures change, the grey boundaries between obsessive personalities viewed as 'normal' today may become pathologised in the future, and vice versa. With the diagnosis of mental health problems being culturally contingent, Jack's idea that he is lonely rather than mentally ill is an interesting privileging of emotional explanations for bodily differences rather than medical explanations.

It is also important to highlight that understanding bodily differences through a medical framework sometimes perpetuates the idea that an 'ideal' body should be strived for by everyone. This ideal is informed by medical knowledge about what a healthy and ideal body is and does. For example, although body mass index (BMI) does not measure health, this calculation of height-weight ratio results in bodies being approved of or condemned on the basis of whether your weight is too high/ too low or satisfactory (Evans and Colls 2009). This monitoring of BMI ensures that individuals and populations are disciplined by medical professionals into understanding what an ideal bodily constitutes (Evans and Colls 2009). Evans and Colls' (2009) research therefore problematises dominant medical frameworks in which particular bodies are privileged.

Despite there being good reasons to contest medical knowledge, as explicitly highlighted in the previous two paragraphs, this section has also demonstrated the difficulties and consequences of doing so. The dominance of medical modes of thought in both clinical encounters and wider society means that any contestation of medical diagnoses often has negative impacts for individuals. This was illustrated in the case of James who had to accept medical diagnoses he disagreed with in order to access education. The experiences of these participants indicate that the process of diagnosis is troublesome for some people negotiating multiple and contested illnesses and/ or disabilities. In this sense, the dominance of typical modes of diagnosis that silence the voices of those with multiple, contested ill and disabled bodies needs to be challenged.

Alongside discussion of people's experiences of both the 'failure' to achieve diagnoses and the contestation of medical diagnoses, the third strand of this section centres on the idea of 'hidden diagnoses'. Reflection on participants' negotiations of multiple illnesses and/ or disabilities makes us aware of the fluctuating prominence of any particular illness or disability in relation to the presence of other illness and disability diagnoses. A central tenet of diagnosis is the idea that symptoms are 'presented' to a clinician who will then seek to identify the 'problem'. However, the 'presence' of multiple illnesses and/ or disabilities sometimes obscures particular 'presentations' of illnesses and disabilities at particular times, and in particular spaces.

This idea is explained with reference to the existing literature that emphasises the variability of ill and disabled bodies (Price and Shildrick 1998). Von Peter (2010), for example, has questioned the idea that illnesses can be considered as straight- forwardly 'chronic' in nature. Referring to a medical case study of a 35 year- old woman diagnosed with "chronic psychotic disorder", it is suggested that the variability of her embodied acts undermines common notions of chronicity (Von Peter 2010). Indeed, it is important to question the idea that bodies are ever 'stable' and 'fixed', even if this perception is widely held. As Price and Shildrick (1998) explain, often the overt demonstration of bodily variability is met with surprise, confusion and (sometimes) resistance. This was evident to Price and Shildrick (1998) when they physically swapped places with each other between a lectern and a wheelchair during conference presentations. The fact that the audience was shocked by this communicates the persisting belief that ill and disabled bodies are, or at least, should be, stable and fixed over time. In this sense, the very idea of 'chronic illness' is problematic because it suggests the presence of a consistent and linear bodily narrative across the life course (Von Peter 2010).

With this literature as its foundation, I argue that an attendance to the intensely variable nature of multiple illness and disability experiences is important in seeking to understand participants' experiences of diagnosis. The biomedical model of diagnosis is challenged by the impossibility of isolating the 'presentation' of any one illness or disability during clinical encounters (and in other settings). This idea is well explained through consideration of Kirsty's experiences of OCD, anxiety and depression, as follows:

*Lindsay: "When did you first think that you had OCD?"*

*Kirsty: Well I had a breakdown... and I was very depressed. I wasn't really functioning at all. So, at first I thought that doing simple things was difficult because of the depression. But when I eventually got some medication that worked- and I began to get glimpses of things being a bit clearer, being able to think a bit more clearly- I realised... that I'd got a problem.*

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*Lindsay: ... so you have OCD and depression?*

*Kirsty: yeh. I have depression and anxiety.*

*Lindsay: ok*

*Kirsty: Em, the depression was the first thing that was obvious when I was really ill, when I was suicidal and had the breakdown. I just wasn't functioning and then, as the anti-depressants kicked in, ... I was beginning to do more things. And it then became more obvious that it wasn't the [depression]-. Because when I was trying to-. Say I was making a cup of tea- the depression was really bad, I couldn't think clearly. It was like being in the dark, in the fog and just not being able to think clearly. So I couldn't think to do things in the right order- like fill up the kettle then get the teabag. [I was] just doing things in the wrong order and not being able to think and not being able to coordinate. And as that began to be slightly more automatic and a bit clearer, it became obvious that I was then having to get the kettle in the right place and the mug and do something with the teabag and time it and all these sort of things."*

From Kirsty's experience of mental health problems, actually diagnosing any one condition is complicated by the existence of others. Kirsty explains that OCD was not recognisable (by either herself or other people) until her depression was treated with medication. This is interesting because Kirsty seems to suggest that two illnesses/ disabilities can be present at any one point in time but that one has the ability to 'hide' the other from recognition. One of the difficulties with this idea is that it is not clear when the second illness/ disability developed; perhaps it developed at the same time as the first or perhaps it developed much later. But in Kirsty's explanation she emphasises that the challenges of the initial depression made it difficult to think clearly enough to undertake the necessary steps to make a cup of tea. This differs from the later challenge of having to order the kettle and mug correctly, with these symptoms of OCD becoming more obvious after the depression had eased a bit.

Kirsty had difficulty in making a cup of tea in both instances but she narrates a different cause to the difficulties in each case. This demonstrates that one symptom or diagnosis may be obvious or privileged at a certain time. Interestingly, a second symptom or diagnosis may not be obvious or privileged in a particular setting, at a particular time. In Kirsty's account, her experience of OCD is emphasised at one point in time but her experience of depression is emphasised at another time. Thus, Kirsty's experience destabilises the notion of chronic illness as understood as a linear narrative in favour of a theorisation of time "linked to performed activities and processes, resulting in an individualised temporality of change" (Von Peter 2010: 23). Hence, discussion of this idea of 'hidden diagnoses', or diagnoses that become more or less obvious in relation to other illnesses and/ or disabilities, undermines a model of diagnosis that relies on the 'presentation' of all symptoms. This idea of 'hidden' illnesses and/ or disabilities prompts us to reflect on the spaces and times in which particular illnesses and/ or disabilities become prominent. Importantly, manifestations of multiple

illnesses and/ or disabilities may become more (or less) 'hidden' in different settings. Although discussion of this topic has not been the focus of my research, future work could further investigate the idea of variability in the degree to which multiple illness and disability combinations work to conceal or reveal other forms of bodily difference.

To conclude this section, I have sought to demonstrate the ways in which research participants' experiences of multiple illnesses and/ or disabilities present a challenge to the dominant model of diagnosis. The application and value of such a model- that relies on the 'authority' of clinicians, the passivity of patients and the 'isolation' of symptoms- for people negotiating multiple illnesses and/ or disabilities is called into question. The clinical spaces of diagnosis have been shown to be especially troublesome for (i) those who have not 'achieved' a diagnoses, (ii) those who contest diagnoses and those with (iii) hidden illnesses and/ or disabilities. Of particular concern is the voicelessness that participants feel in the process of diagnosis, despite its implications for their lives.

## 5.4 Treatment

As well as these difficulties in negotiating processes of diagnosis, I also argue that treatment experiences present a significant challenge for people living with multiple illnesses and/ or disabilities. In this section, two aspects of this difficulty will be explained with reference to the experiences of Stephanie, Vicky and Angela. Firstly, it will be shown that, in the context of particular diagnoses being associated with particular treatments, a determination of the most appropriate or relevant treatment may be based on the (perhaps contested) high importance and urgency attributed to any one symptom or diagnosis, at the expense of other symptoms/ diagnoses. Secondly, this approach of isolating the most important and urgent diagnosis to treat means that the best course of treatment for one diagnosis may actually worsen the person's experiences of other diagnoses. Hence, any treatment provided to people with multiple illnesses and/ or disabilities has implications for the whole emotional and material body, rather than just in relation to particular component diagnoses. This point is one which exposes the difficulty that participants in this research had in 'fitting into' treatment spaces.

To begin with, linked to the discussion presented in the previous section, the interdependence between diagnosis and treatment experiences is worthy of further examination here. Just as the voices of those of those people without clear-cut medical diagnoses are often dismissed by others, such as Vicky who negotiated multiple illness

identities in the absence of any diagnoses, so too are some of their treatment experiences characterised by feelings of rejection (Johansson *et al.* 1996). There has already been some work conducted on this by Johansson *et al.* (1996) who interviewed women living with biomedically undefined musculoskeletal disorders in northern Sweden. Particularly revealing is a quote from one woman who Johansson *et al.* classify as feeling 1) ignored, 2) disregarded and 3) rejected in clinical settings (Johansson *et al.* 1996). It's valuable to repeat the quotation here:

"When the doctor arrived, he had a ready-made diagnosis and *didn't listen to what I said*. I talked to him about my back pain and how I perceive that the trouble in my feet and legs is connected with the spine. *He said that was pure rubbish*. I found him brusque and unkind. And I was frightened and worried. He wanted to give me psychic drugs, antidepressants. I said I didn't want that. He sat down to write a prescription *without further explanation*. I asked for sleeping pills, but he refused. He prescribed vitamin B and something else *he didn't explain*, then he left. I felt that *I'm not welcome* in the health care system. I used to think I should wear a little tinkle bell like those infected with the plague long ago in the past. I could jingle the bell to give them all a chance to run away, all of them." (Johansson *et al.* 1996: 499, original emphasis).

This quotation clearly communicates the interdependence of diagnosis and treatment experiences. Given that this patient's symptoms were completely dismissed by her doctor, accessing desired treatments became impossible (Johansson *et al.* 1996). This is quite a simple yet important point to make. Indeed, in the context of particular diagnoses being associated with particular treatments, people living with multiple, unexplained or contested illnesses/ disabilities do not easily 'fit into' the health care system. As the patient quoted by Johansson *et al.* (1996) explains with reference to 'the plague', medical staff just did not want to engage with her.

Disagreements about the relevance and importance of particular treatments also feature prominently in accounts given by participants in this research. With reference to Stephanie's experience, it is clear that patients and medics sometimes have different perceptions about the urgency of treating any one aspect of bodily difference:

*"So when I was diagnosed with clinical depression and suicidal tendencies at that time, I felt like the bulimia just got swept under the carpet like it didn't matter. [But] in terms of what I actually did and what was affecting my life on the most frequent basis, it was definitely bulimia. But the one that they were worried about, in terms of severity of consequences, was*

*depression and suicidal tendencies so I sort of felt like some of the things that I did that I felt were about the bulimia were classed as being about the depression now. And I'm not saying that they should have been pushed back into the bulimia category. But, rather, you can't neatly define up what is agoraphobia, what's bulimia, what's depression, what's OCD or anxiety disorder."*

Stephanie's experience demonstrates the politics of urgency that is negotiated in clinical encounters. Even though Stephanie experienced bulimia, it was the diagnosis of depression that was viewed by her doctor as the most important to treat. Furthermore, within the context of negotiating urgency, Stephanie describes a situation where the boundaries between the depression and bulimia experiences are redrawn by her doctor. Indeed, even though she attributed some experiences to a diagnosis of bulimia, in the context of the medical encounter these experiences were categorised as symptoms of depression.

This rearticulation of the boundaries between the two illnesses is reminiscent of Agamben's (2005) description of a 'zone of indifference' (Agamben 2005: 23) where the law is both suspended and simultaneously in operation. Following Amoore's (2006) argument in relation to the production of 'biometric borders' (for example, using databases of finger prints at airports), the border is strategically imagined as an easily definable and clear cut line between acceptable and unacceptable bodies. Not only can this line not be drawn, but it is constantly being re-drawn (Amoore 2006). Although written about in a different context, Amoore's (2006) work is highly relevant to understanding the politics of Stephanie's experience of both bulimia and depression. Clearly, the clinician communicated the idea that Stephanie experiences two different conditions. Yet, the boundaries between the 'more serious' depression and 'less serious' bulimia are constantly reimagined and renegotiated as both Stephanie and her doctor classify particular aspects of bodily difference as belonging to either one illness/ disability or another.

Of course this redrawing of the boundaries between symptoms of depression and bulimia, is part of the process of establishing and re-establishing hierarchies of bodily difference that directly relate to the perceived urgency of treating particular symptoms. A diagnosis of depression with suicidal tendencies is viewed as a more immediate danger to life than bulimia. This is despite the fact that Stephanie perceives bulimia as the most urgent condition to treat, on the basis that she is affected by it most frequently. This tension over establishing the urgency of treating any one illness/ disability over another is a reflection of the compartmentalisation of particular diagnoses, to the detriment of understanding bodies more holistically. Hence, Stephanie's experience foregrounds issues of contested

importance and urgency in negotiating treatment amongst people living with multiple illnesses and/ or disabilities. In this sense, those negotiating multiple illnesses and/ or disabilities present a challenge to the organisation of treatment in clinical settings, a challenge in which the unequal power relations between clinicians and patients to define the terms of diagnosis and treatment has to be acknowledged.

Adding to this point, the second strand of discussion in this section focuses on the implications of trying to treat any one diagnosis in isolation from the rest of the body. Specifically, as will be demonstrated with reference to Vicky's experience of trying to access treatment and Angela's experience of being treated for one of her illnesses/ disabilities, attempting to treat an 'isolated' diagnosis can be hugely frustrating and distressing for patients. The key argument here is that people living with multiple illnesses and/ or disabilities are sometimes viewed by clinicians only in terms of singular, narrow diagnoses, and their corresponding treatments, rather than in terms of their wider bodily experiences and needs. To explore this issue I will refer to the experience of Vicky, whose difficulty in achieving a diagnosis was described at the beginning of the chapter. One of the reasons why Vicky's difficulty in achieving a diagnosis was so problematic was because of the repercussions this had for accessing treatment, as she explained during our interview:

*Lindsay: "...do you have any other points you think are quite important for the research? Do you see OCD as 'belonging' within other categories like 'mental health' or 'disability'? Or is it more of a mix of categories?*

*Vicky: Em, I think it's difficult because I sometimes refer to myself as having OCD and I sometimes refer to myself as having an eating disorder.*

*Lindsay: right*

*Vicky: and for me that seemed quite natural because, when I looked it up, to have an eating disorder you have to eat for psychological reasons- not for physical reasons.... well that's me down to a T [that's me 'exactly']. And I think I have an eating disorder, as well as OCD. And I had an appointment with an eating disorder clinic which is actually where I wanted to go- I wanted that over CBT. I wanted to talk to people- [about] the physical eating side of it because that was the problem, not the behaviours. Their reason for turning me away from an eating disorder clinic was because I didn't have a problem with weight or body image and that made me quite angry that the definition of an eating disorder in the eyes of the NHS is- you can go to an eating disorder clinic if you have an issue with weight or body image. And*



*that was something I struggled with on a day to day basis was: 'I have OCD, what about eating?'... that needs to be addressed... if OCD can relate to anything I think I should have been able to go to an eating disorder clinic to talk about my relationship with food. Like, where else is better to do that, realistically, than someone trained to talk to people with eating disorders? But I wasn't allowed to do that."*

The rejection and uncertainty that Vicky experiences underscores the emotional implications of negotiating multiple, contested illness and disability identities in treatment settings. In my discussion about the impacts of treating a singular diagnosis in isolation from the whole emotional and material body, it will be shown that some treatment processes can be highly damaging to patients, despite appearing to be of benefit in the treatment of any one illness or disability. To make this argument, a reading of the emotional geographies literature is important because:

"Our emotional relations and interactions weave through and help form the fabric of our unique personal geographies. We live in worlds of pain or of pleasure; emotional environs that we sense can expand or contract in response to our experience of events—though there is rarely a clear or consistent sense of simple 'cause' and 'affect'." (Davidson and Milligan 2004: 523- 524)

The rise of work on emotional geographies can be understood as a critique of dominant 'rational' academic knowledge that has partitioned emotion as outwith the realms of scholarly enquiry (Bondi 2005). Unfortunately, discussion of emotions has historically been viewed as irrelevant and of little value in the academy (Widdowfield 2000). However, by paying attention to the emotions associated with the negotiation of multiple illness and disability identities, we are able to unpick problematic treatment practices and geographies that have emotionally damaged some participants in this research.

If we consider Vicky's experience, we realise that it is heavily laden with emotions; this is clearly evident from her use of words such as 'difficult', 'angry' and 'struggled'. Following Davidson and Milligan (2004), Vicky's personal geographies can only be understood through a recognition of the emotional experience of being rejected from the treatment setting she wished to attend. For me, this demonstrates the process of accessing treatment as very difficult for those with multiple, contested and unexplained illnesses/ disabilities. But just as academia has not focused on 'the emotional', wider society similarly rejects the display of particular emotions at particular times/ spaces. For example, in Parr, Philo and Burns' (2005) research about people with mental health problems in rural and remote parts of the Scottish Highlands, they highlight how the unacceptability of showing emotions works as a way to

discipline people with mental health problems into not revealing diagnoses (Parr, Philo and Burns 2005). They research how mental health problems (including anxieties, depression and other emotional and psychological states) are typically denied by both the people experiencing and those witnessing the problems (Parr, Philo and Burns 2005). This “culture of silence and resilience” (Parr, Philo and Burns 2005: 94) highlights how emotions can be socially placed, with one consequence being the difficulty in accessing treatment (Parr, Philo and Burns 2005).

From this example it is clear that “silencing” can make it difficult to acknowledge emotions and access treatment. For Vicky, the denial of treatment for an eating disorder made her angry, but this was not addressed during clinical encounters. Davidson’s (2005) research about experiences of people living with phobias confirms this sense that, as a contested illness, phobias are often denied by other people, including medical professionals. This again means that the stigma of such an illness/ disability is perpetuated and the lives of people with those experiences are often made more difficult. Attending to the emotional implications of trying to negotiate treatment settings for people with multiple illnesses and/ or disabilities, the power of medicine comes into sharp focus. As Ahmed (2004) argues:

“Attention to emotions allows us to address the question of how subjects become *invested* in particular structures such that their demise is felt as a kind of living death.” (Ahmed 2004: 12).

This idea of ‘investment’ is interesting when considering Vicky’s experience of negotiating OCD and eating disorder identities. Vicky explains that the definition of an eating disorder is “me down to a T [me exactly]”, emphasising the connection she felt between the definition used and her specific experience. Vicky ‘invested’ in the idea of experiencing an eating disorder and it became an important part of her identity, such that she notes the high level of consistency between the description of an eating disorder and her personhood, that “it seemed quite natural”. When this invested identity was challenged, Vicky became angry. Hence if access to diagnosis and treatment are theorised as legitimising practices through which patients can confirm particular perceived identities, the emotional consequences of medicine dismissing an aspect of a person’s identity can be huge. The denial of Vicky’s access to a particular treatment setting for people with eating disorders underscores the upsetting and damaging emotional geographies of some treatment experiences for people negotiating multiple illness and disability identities.

As well as in the context of trying to access treatment, it is also important to consider the experiences of people within treatment settings. As will be demonstrated, the focus of medical practitioners on the treatment of isolated illnesses/ disabilities can be hugely

problematic for some people experiencing multiple illnesses and/ or disabilities. For example, Angela's experience highlights some of the difficulties associated with the treatment of one illness at the expense of another:

*Lindsay: "how long were you in hospital for the first time?"*

*Angela: a couple of months*

*Lindsay: a couple of months*

*Angela: yes- I was. First I was in the medical unit then I went to [names another unit]*

*Lindsay: and how did you find it when you were in the hospital? What did you think of it?*

*Angela: it was hell. It was hell because it was constant interaction with people- there was other people constantly there so, for someone with extreme social anxiety, that was just- The way I moved, everything I said, everything, even the way I lay in bed. I used to think 'oh gosh people will think I'm this or that'. And no amount of CBT can, kind of, override that because it's almost like a gut instinct that's there."*

Whilst Angela was in hospital to treat one of her illnesses/ disabilities, her experience of social anxiety was particularly acute and this caused her huge distress. She notes that there was constantly someone in the same space as her and that she felt judged by them. Although there has not been much qualitative research conducted about people's experiences of multiple illnesses and/ or disabilities in various treatment settings, recently Claes *et al.* (2013) wrote about the life histories and life trajectories of people with intellectual disabilities *and* mental health problems in Flanders, Belgium. In this interesting piece of work we get a sense of some of the difficulties involved in treating people with multiple illnesses and/ or disabilities. For example, they explain that having intellectual disabilities is often an exclusionary criteria for accessing mental health services, and vice versa. This prompts us to question the processes through which access to treatment becomes possible or impossible in relation to 'other' aspects of a person's body and identity that may be considered inconsistent with (or even 'clashing' with) treating any one illness or disability.

In the case of Angela, although she was not physically 'excluded' from one treatment setting because of one of her other diagnoses (in contrast to the case described by Claes *et al.* (2013)), I argue that she was excluded in other ways. After all, social space is (re-)

produced on the basis of who is felt to belong and to not belong (Sibley 1995). Given that Angela's social anxiety did not seem to be accommodated in any way, such as by providing a separate space for her away from other people, clearly the social space is (re) produced as belonging to people with a particular diagnosis to the detriment of people with other illnesses and/ or disabilities that need to be taken into account.

This production of this space is constantly (re) negotiated. In the case of experiencing multiple illness and disability identities, people may be moved from service to service based on the constantly changing hierarchy that privileges any one aspect of an identity over another, depending on its perceived urgency and importance. This is often a form of forced and highly morally ordered mobility with particular movements narrated positively and others viewed more negatively. For example, being asked to leave an organisation and move to another has negative connotations but a referral from a psychiatric institution to home is viewed in a positive way (Claes *et al.* (2013)). For Angela, there was little choice about her going into hospital and this forced mobility did prove to be "hell" for her.

Angela's experience can also be understood as a sort of coerced immobility. Whilst Angela did have to move into hospital, she could not move out of it for a couple of months, and as such, it became a kind of home. In Mizrachi's research (2001) about an institution in Jerusalem, Israel, that serves 'severely handicapped' children, the author notes the unstable nature of the place's identity as a hospital, educational facility and a home. Clearly, in this case, any given idea of what typically happens in these different settings produces conflicts about what should happen in an institution where all these place identities merge. Similarly, Angela's immobility from hospital means that it also becomes 'home' for a couple of months, but a 'home' she characterises as 'hell'. Any one place can be understood through multiple, sometimes conflicting, narratives. Whilst hospitals may be thought of as a place of treatment and recovery for some, for Angela in negotiating her multiple illness and disability identities, it was a very difficult place to be because of her extreme social anxiety.

Thus, in attempting to isolate a particular diagnosis within the body and then treat it accordingly, the wider health and emotional needs of a person are still important; they do not simply disappear when the choice is made to treat one particular diagnosis. The idea of treating one illness and/ or disability at the expense of another underscores the extent of the difficulty that people negotiating multiple illnesses and/ or disabilities have in negotiating spaces of treatment. The current organisation of such spaces has to be called into question, given that participants in this research struggle greatly as a result of the dividing up of treatment processes as corresponding to particular (problematic) divisions of aspects of

bodily difference.

In conclusion, this chapter increases awareness of the wide- ranging difficulties that people negotiating multiple illness and disability identities routinely experience when seeking diagnosis and treatment. The current organisation and practice of diagnosis and treatment is challenged because of its rootedness in modes of thinking that are inconsistent with the difficult bodily variabilities that participants in this research experience. Clinicians' tendency to try to isolate particular diagnoses from other diagnoses leave people negotiating multiple illnesses and/ or disabilities feeling excluded from some diagnosis and treatment processes. This was shown to be hugely damaging to the emotional wellbeing and sense of identity for participants in this research and prompts reconsideration of the organisation of spaces of diagnosis and treatment to 'make room' for multiplicity, contestation, ambiguity and uncertainty.

## Chapter 6: Messy mobilities

### 6.1 Attending Waddington Street Centre: Hannah's experience

*With my heart pounding and sweat pouring off me onto my fresh sheets, I woke up in a panic for the third time in as many hours. I'd already been through this issue 'logically' in my mind time and time again, reaching the same conclusion each time: I must try to at least visit Waddington Street Centre. As part of my recovery from severe anxiety and depression my community psychiatric nurse (CPN) and support worker were really pushing for me to get into a routine, meet new people and participate in meaningful activities. I wasn't so sure.*

*Although I eventually started speaking to some of the other patients when I was in hospital, I found it very difficult at first. I would love to be able to just start speaking to strangers but if I try then I clam up, say something stupid and then spend the rest of the day regretting it. Nevertheless, if there is a way to get past these cycles of severe anxiety and depression then at least visiting a mental health resource centre, such as Waddington Street Centre, might be a helpful first step. After all, I would have my support worker- Karen- with me by my side at every stage.*

*But today was that long anticipated day on which I would actually have to go through with visiting the centre. It had become very real. But maybe I could postpone my visit? Maybe I could fail to answer the door when Karen arrives to pick me up? Maybe I could say that that I have food poisoning/ the flu/ a headache or some other problem that would mean I don't have to go to Waddington Street Centre today. But it was time to get up and I made a deal with myself that I will at least get up and dressed before deciding whether or not to attend.*

*As I took my morning pills and injected my leg with the insulin needed to control the diabetes I'd endured all my life, the doorbell rang. Karen was early! It would be even more difficult to get out of attending now. I quickly answered the door and let Karen in before going to the toilet. Accessing toilets was another worry I had. The double whammy of living with diabetes and being constantly stressed means that I have to know that I can easily get to a toilet. Even going on a 15 minutes bus journey had to be carefully planned around toilet visits. After going to the toilet, Karen and I set about leaving the house and proceeded to the nearby bus stop.*

*When I got onto the bus and after being grunted at by the unfriendly driver, I had to make the usual decision about where to sit. I wanted to sit near to the front of the bus so I would*

*be able to see the exit but I didn't want the other passengers to think badly of me for sitting on a seat which is really reserved for elderly or disabled people. I definitely wasn't elderly (at aged 37) and although I received disability benefits, nobody else on the bus could see that I wasn't 'normal'. As a compromise I decided that Karen and I would sit near to the front but not at the very front of the bus. Luckily the bus wasn't too busy and Karen didn't have any requirements of her own!*

*The bus journey actually went quite quickly and as we got off the bus I still wanted to back out of attending Waddington Street Centre. I just didn't know what to expect. Karen told me that the staff and volunteers are very friendly. There were also a lot of activities that I could attend. I liked the idea of attending the art class but that even contemplating that was a long way off! I enjoyed art at school but knew I wouldn't be good at it now. Karen also mentioned that there are a range of books available to borrow and there is a café to buy food and drink from.*

*All of those features would be enough to 'sell' the centre to most people but I still had so many nagging doubts about whether I would be suited to the place. What if the other service users don't want to talk to me? Perhaps they already have friends and don't feel the need to make more. What if people think that I'm either too mentally ill to attend Waddington (and that I should really be in hospital) or that I'm not ill enough to be here and that I should be out getting a job and paying tax? What if people ask me about why I became depressed and attempted suicide on several occasions, despite the fact that I had what other people would see as a relatively good life? As I walked through the entrance to Waddington Street Centre it felt like I was about to set foot on another planet, with all the associated risk and worry. But also I felt like coming to Waddington was potentially a new beginning and an opportunity for me to live a different kind of life.*

## 6.2 Negotiating distances

This fictional account of Hannah's experience of attending The Waddington Street Centre for the first time is a testament to the anxiety that many interview participants felt about attending new places. A key theme woven into the story of Hannah's difficulty in attending this new place is that of *mobilities*, and particularly the often unspoken and different mobilities that people with multiple illnesses and/ or disabilities experience when "passing through other people's spaces" (Hansen and Philo 2007: 495). For example, when Hannah expressed uncertainty over where she should sit on the bus, this was done so with reference to the expectations she thought the other passengers would have about where a 37 year-

old female with no visible disability should locate herself on public transport. Clearly, particular socially expected and accepted mobilities do shape everyone's life experiences, but how do the participants in this research actually experience and negotiate mobilities that may disrupt the 'normal' timings, spacings and flows of people and objects (Hansen and Philo 2007)?

The discussion presented in this chapter seeks to build on the work of the previous two empirical chapters that demonstrated the terms on which people negotiating multiple illness and disability identities understand their bodily differences as, firstly, incomprehensible and, secondly, undermining clinical spaces that seek to neatly compartmentalise individual bodily symptoms. Following these arguments, this chapter turns to address how participants use these understandings (and 'lack' of understandings) about their ill and disabled bodies to function in (perhaps in different ways to the societal norm) their lives. One way to think about this is in relation to the mobilities of research participants, as a key theme discussed in the interviews with participants. My interest in the topic (and hence why I asked about it in interviews) is a reflection of the growing academic attention placed on mobilities (Hannam *et al.* 2006). This increased interest is understandable, given that the movement of people, ideas and objects "...lies at the centre of constellations of power, the creation of identities and the micro-geographies of everyday life" (Cresswell 2011: 551a).

Indeed, thinking about these power geometries is central to understanding the mobility experiences of the participants taking part in this research. Crucially, it is the *relative* mobility of individuals and groups that marks out the inequality shaping people's daily lives (Adey 2006, Bissell 2009b). In contrast to transport geography- with its spatial science traditions- the mobilities literature is more than about working out how to efficiently move people from A to B (Cresswell 2011a). Indeed, we need to consider: "Who moves, who stays, under what conditions?" (Fortier *et al.* 2003)

Whilst transport geography has tended to theorise bodies as discrete entities independently moving through space (Law 1999), it is important to consider the interdependencies of mobilities. For instance, a train passenger travelling with a baby also has to negotiate buying tickets, visiting the toilets and getting onto the train all whilst carrying and attending to the needs of the baby (Law 1999). Further, in relation to travelling with suitcases and other mobile prostheses, Bissell's (2009b) research on the East Coast mainline in the United Kingdom highlights tactics that passengers use to move through the spaces. For example, a passenger may distribute luggage in particular ways in order to ease the pressure on her body (Bissell 2009b). Hence, undermining theorisations of bodies as



independent entities marks a departure from the 'billiard ball' notions of people and movement.

Whilst Cass *et al.* (2005) highlight the four dimensions of access to spaces as financial, physical, organisational and temporal, there is much more scope to develop understandings about the ways in which emotions shape mobilities. Indeed, as mentioned in *Chapter 2*, within disability studies there is some work being developed around the concept of 'psycho-emotional disablism'. Whilst we may be more familiar with what Reeve (2012) describes as the structural aspects of disablism (including inaccessible environments, exclusion and discrimination), it is also important to attend to the emotional implications of being humiliated, pitied and hurt by the opinions of others operating in a society where some people are prejudiced towards people with disabilities (Reeve 2002). There are direct psycho-emotional aspects of disablism, such as being stared at or joked about by strangers (Reeve 2012). But there are also indirect examples of psycho-emotional disablism, including the ensuing distress or anger of being physically excluded from a building because it has not been built in an accessible way (Reeve 2012). These emotional aspects of being discriminated against certainly shape the mobilities of people living with disabilities, as will be further demonstrated in this chapter.

More broadly, there has been a focus on the links between emotions and health within the social sciences. For example, Conradson's (2005b) research about the emotional encounters experienced by visitors to a respite centre located in a large wooded area of Dorset, England demonstrate that altering daily routines can invoke a sense of freedom. The respite centre's guests typically experienced some form of disability and saw their visit as a way of distancing themselves from everyday routines and demands, thus enabling a sense of calm and reinvigoration (Conradson 2005b). This focus on the importance of a change of routine, underscores the emotional dimensions of mobilities (Conradson 2005b) alongside the literature emphasising imaginations of emotions, self and landscapes. Indeed, Cresswell (2011b) argues that the discipline of geography has not paid much attention to mobilities, despite much discussion of the concepts of landscape, space and place. It is the emotional aspects of changes in routines such as those mentioned in relation to the experiences of people with disabilities in a Dorset respite centre (Conradson 2005b) that underscore the importance of attending to the emotional aspects of mobilities alongside the emotional aspects of landscape.

Considerable attention has also already been paid to the emotional mobilities of migration. For example, in interviews with gay and lesbian Australian migrants, Gorman-Murray's (2009) research participants emphasised the importance of comfort and love in choosing to

relocate to another place. However, the experience of transnational migration may also be characterised by feelings of loss and homelessness (Svašek 2010). As well as thinking about the emotional mobilities of migration, I think it's also important to consider the emotional dimensions of movement in other parts of people's lives. Specifically, thinking about people living with multiple illnesses and/ or disabilities, attending to the emotional aspects of everyday mobilities underscores the messiness of mobilities.

As with all of the other empirical chapters in this thesis, the first aim of the chapter is to set out some of the experiences of people living with multiple illnesses and/ or disabilities. From there, the participants' accounts of their mobilities will be used to add to the literature about what the *relative* mobilities of participants can tell us about the nature of mobilities in general. Specifically, I seek to respond to Andrews *et al.*'s (2012) call for those working in the geographies of health to conduct research about the complexity of movement experiences (including the experiences of people with chronic illnesses and disabilities), beyond assessing particular behaviours or generic movement patterns. To answer this call, I want to explain the messiness of mobilities amongst the research participants, further undermining the positivist legacies of transport geography that assume movement is always easily understandable and logical. Crucially, the benefit of undertaking this task is that just as "part of hearing the experience of disabled people is hearing the internal conflict, the ambivalence, the collusion, the confusion," (Watermeyer and Swartz 2008: 609), we become aware of the sometimes irrational, uncertain and ambiguous nature of mobilities.

To achieve this end, the chapter will be structured around the themes of: a) imagining distances, b) experiencing public transport and c) transgressing accepted and excepted mobilities. These issues are foregrounded in this chapter because of the importance they had in the lives of several participants in this research. Crucially, distance- and mobilities in general- are understood as subjective, fluid and relational rather than viewing the separation between people and places as straight- line distances in Euclidean space (Curtis 2010). The structure used in this chapter will enable communication of the 'messiness' of both mobilities and (specifically, ill and disabled) bodies.

### 6.3 Imagining distances

"The inequities of mobility and movement are connected to sociocultural values and practices which prioritise mobile bodies or those characterised by societally defined norms of health, fitness, and independence of bodily movements." (Imrie 2000: 1641)

Geographers and others have sought to underscore huge inequalities in physical access to the built environment (for examples, see Gleeson (2001), Imrie and Kumar (1998) and Kitchin and Law (2001)). These 'inequities of mobility' (Imrie 2000) can be understood in both structural and psycho- emotional terms (Reeve 2002). In this section of the chapter it will be argued that research participants' imaginations of distance are shaped by both the material and emotional dimensions of various mobilities. The 'messiness' of mobilities is apparent in terms of the highly changeable and complex imaginations of distances expressed by participants. Indeed, as will be discussed, distance is understood in the context of 'messy bodies' negotiating emotion-laden financial and temporal dimensions of mobilities.

An absence of reflection about the "leaky, messy, awkward zones of the inside/ outside of bodies and their resultant spatial relations" (Longhurst 2001: 2) is linked to the dominance of masculinist modes of knowledge production (Longhurst 2001). For example, the onset of menstruation and the 'mess' created as a result of blood loss is understood by some in masculinist terms as the beginning of a volatile and uncontrollable bodily state (Grosz 1994). But paying attention to the messiness of bodies underscores the uncertainties and irrationalities (in both emotional and material terms) of mobilities.

Certainly, the imagined and material messiness of bodies had some quite profound impacts on the mobilities of participants. It should be noted that I felt as though some participants 'held back' some detail on these issues (see *Chapter 3* about some of the reasons why this might have been- and particularly discussion about silences in relation to Angela). However, Mark does articulate the relationship between his anxiety, chronic pain and irritable bowel syndrome (IBS) in navigating his journey from home into a town in the North- East of England:

*Lindsay: "So maybe to start with... maybe you could run through what you did yesterday or... maybe a typical day. What do you do each day?"*

*Mark: right, well a typical day- now I'm governed by what i can and can't do because of [bodily pain]*

*Lindsay: right*

*Mark: and I've got irritable bowel syndrome*

*Lindsay: right*

*Mark: that adds to my anxiety because some days I can leave the house and some days I can't.*

*Lindsay: right*

*Mark: because they've changed the bus timetables and it means that I'm going to be stuck on a bus for an hour which- with irritable bowel and [bodily pain]- it's not really much of an option, you know?*

#### *LATER IN THE INTERVIEW*

*Mark: [I can't guarantee] to be where I have to be at a certain time*

*Lindsay: yes*

*Mark: because... I might be half way up the garden path and I've got to double- back to the toilet... [then my] bus [is] missed*

*Lindsay: uhu*

*Mark: you know? So the anxiety- if it comes out with... your [chronic pain] and your bowels."*

As Mark demonstrates, it was the combination of multiple illnesses and/ or disabilities that shaped his ability to move from his home into a nearby town, in addition to the structural aspect of public transport timetabling. For example, at one point he explains that sitting on a bus for an hour is not possible because of both the pain involved and because of having irritable bowel syndrome (IBS). Additionally, the decision to travel on any given bus is subject to constant change- right up to the point of departure. This variability in his illness and/ or disability experiences, coupled with the restrictions associated with bus timetabling, reveals the highly emotional temporalities shaping Mark's mobilities.

Particular mobilities are associated with particular bodies. As Kitchin and Law (2001) argue, being unable to go to the toilet when necessary can be theorised as a dismissal of rights to dignity. But the extent to which access to toilets is 'necessary' becomes tied up with notions about the temporal distance in which bodies are expected to go without toilet breaks.

Indeed, some may view local bus journeys as operating over 'short distances' that do not require the provision of toilets, unlike the accepted norm of providing toilets on 'long distance' bus and train journeys. But Mark's need to access toilets without much notice means that he is both always hesitant about travelling on the bus, and sometimes unable to travel on any given bus. Clearly, gauging the necessity of providing toilet access is based upon normative understandings of bodies as able to be contained from leaking within supposedly 'short' time frames; across 'short' distances.

Mark's experience also highlights the *relative ease* of (this particular) bus mobility amongst those with bodies that conform to societal norms about the containment of liquids; in stark contrast to the *relative difficulty* of moving (by this particular method) amongst those with less easily containable bodies across supposedly 'short' distances. This difference in the ease or difficulty of mobility is not just understood in practical terms. Although Mark's emotions may not be immediately apparent to the reader of his quotation (above), listening to his voice in the interview recording reveals what I sensed to be quite a high level of frustration about having to live with such unpredictable illness and disability experiences, whilst also trying to adhere to a predictable bus timetable. Certainly, Mark's experience can be understood as a form of indirect psycho- emotional disablism (Reeve 2012) because of the negative emotional consequences (such as frustration) of being physically excluded from his desired form of mobility.

Further, Mark's combination of illnesses and/ or disabilities works quite unevenly over time, restricting his ability to predict the possibility of undertaking a future, desired mobility. The importance of this variability over time comes into focus as shaping particular imaginations of distances. For me, Mark's experience indicates the prominence of interruptions to desired mobilities amongst those living with changeable illnesses and/ or disabilities- resulting in changeable imaginations of distances. As Middleton (2009) suggests, missed buses interrupt the regulated temporal rhythms of travelling, giving us an insight into how sociotemporal worries relate to participants' narratives of identity. In terms of such ideas of identity, and particularly the relational production of identities, Mark does not easily fit into the expected rhythm of daily life. Even trying to make a journey to a nearby town is fraught with the potential for interruptions; thus undermining assumed notions about the ease of 'short- distance' travel.

These interruptions to desired mobilities make us aware of the temporal dimensions of mobility. Additionally, and with reference to Kirsty's experience, I would like to further explore some of the implications of being 'out of step' with dominant ideas about the length of time

that particular mobilities should take. Specifically, we can think about this in relation to Kirsty's organisation of activities over the course of the day:

*Lindsay: "do you find that... [living with OCD] impacts on your energy levels?"*

*Kirsty: Yeh, it's very tiring... things take so much longer. I don't get as much done as other people would...it was taking me three hours in the morning and three hours at night [to go through routines and tasks] so it doesn't leave you much of the day left*

*Lindsay: mm*

*Kirsty: ... and the whole distress and anxiety around it... really takes it out of you."*

Spending six hours per day going through the routines and activities associated with living with OCD means that Kirsty does not 'get as much done as other people would'. So, clearly, this example underscores the importance of considering the knock- on consequences of any one activity taking longer than the expected norm. Secondly, Kirsty's feelings of anxiety and distress at undertaking these OCD- related routines reduce the available energy she has to pursue other activities. Hence, having both fewer hours remaining in her day to participate in other activities and the depletion of emotional and physical energy capacities means that time becomes central to our understandings of distances. Indeed, if there are very few hours left in the day to participate in other activities, the ability to become mobile outside of the home is restricted- sometimes making travel across 'short' distances insurmountable.

Indeed, even if there is theoretically time within the day to participate in activities outside of the home, Kirsty's experience of depression as well as OCD means that she may not be able to leave the house:

*Kirsty : "I'll often not get out of the house to go to the shops... or to anything else I need to do, unless I've got an appointment or I'm meeting somebody... I need that motivation really."*

Hence, Kirsty's OCD and depression experiences mean that supposedly 'short' distances are impossible to travel on some days. In Soldatic's (2013) research in Australia, she explains the ways in which appointments are used to in the context of neoliberal workfare regimes (that people with disabilities must attend) in accordance with socially acceptable rhythms of daily life. Given the unpredictability of many illness and disability experiences, Soldatic (2013: 411) asks: "what happens when our bodily temporal patterns are unable to be synchronized with the multiplicity of rhythmic temporal patterns of everyday life with this forced appointment time?" In Kirsty's case, she sees appointments as motivation to leave the house whilst also acknowledging her inability to leave the house on some occasions. Hence, Kirsty's experience paints quite a complicated picture of mobility. Her imagination of

distances is shaped by the temporal patterns of her daily life, making travelling 'short' distances from home to a 'nearby' town possible on some days but impossible on other days.

In terms of this imagination of distances, particular desired mobilities have been demonstrated as shaped by highly emotional and temporal bodily experiences. Additionally, these imaginations of distance are influenced by financial considerations. Within the context of this chapter's focus on mobilities, the idea of *relative mobility* (Adey 2006, Bissell 2009b) again becomes significant because the unequal distribution of financial resources results in unequal mobilities- and imaginations of distance- between those with and those without illnesses and disabilities. Focusing on economics, we know that- in some instances- the mobility of people is influenced by capacities to pay more than other people for products and services. For example, a biometric system in place in Amsterdam's Schiphol Airport enables business class passengers to move through border controls more quickly than other passengers (Adey 2006). Given that people with disabilities may experience poorer quality education and employment opportunities than those without disabilities (Beresford 1996), this link between economics and mobilities means that available financial resources inform imaginations of distances.

To explain this point further, I provide an extract from an interview with Patrick in which he explains the links between his health, unemployment and possible mobilities:

*Patrick: "...I can't... have a job [that] pays me good money... I can't have what I really enjoy*

*Lindsay: yeh*

*Patrick: ...maybe you can't go on holiday because you haven't got enough money, you can't take a break. I sort of feel robbed to a certain extent- of my life*

*Lindsay: right*

*Patrick: so I feel like I'm robbed of all [those] pleasures I could have had without OCD, you know?"*

Patrick's desired mobility is explained here as the ability to go on holiday. However, his experience of OCD means that he is not currently in employment and, therefore, cannot afford to take a break. This financial element is important because it shows that imaginations of distance may be understood in economic terms. Indeed, for Patrick, the prospect of achieving his desired mobility is financially distant. Clearly, this is emotionally stressful for Patrick, with him explaining that he has been 'robbed' of the kind of life he imagined for

himself.

In this first section of the chapter I have explained some of the ways in which the 'messiness' of mobilities is a reflection of the 'messiness' of (particularly ill and disabled) bodies. Although each example provided demonstrated a different point- from the importance of bodily experiences to time and finances- these examples were also similar in that they always indicated the emotional nature of mobilities. Far from being straight- forward and logical, the mobility experiences of people who participated in this research are characterised by quite 'messy' and variable imaginations of distances that often differ from societal expectations about the management of bodies and movements.

## 6.4 Experiencing public transport

Building on these understandings generated from the previous section about *imaginations* of distances, this section will turn to explore participants' experiences of actually *using* public transport. In other words, I would like to explore what participants experiences are once they are mobile, specifically in relation to public transport use. This aim is consistent with Cresswell's (2011a) suggestion that the mobilities literature is about more than finding the best way of moving people from A to B; we need to consider how people experience particular mobilities. Although I am aware that there are several possible mobilities that I could focus on in this section, I have chosen to examine public transport experiences because many participants discussed the topic in depth, indicating its importance to their lives. I also think- and hope to demonstrate in this section- that paying attention to public transport experiences further reveals the really interesting messiness of mobilities amongst people living with multiple illnesses and/ or disabilities. Specifically, this section will argue that effectively negotiating multiple illness and disability identities whilst using public transport means becoming acutely aware of (physical, social and emotional) surroundings. This awareness is then used to make the best possible decisions about how to cope with a form of mobility that is understood by many participants as deeply anxiety provoking.

Following Gatrell (2013), I argue that just as the 'mobilities turn' has not placed much emphasis on the implications of mobility for health and wellbeing; so too is there scope to develop understandings about the possible impacts that health and wellbeing has on mobilities. Gatrell (2013) notes that geographers have focused on the links between health and place but there is also potential to consider the positive impacts that movement can have on health. Although I agree that much more emphasis could be placed on the links



between mobilities and health, I also think it is important to attend to the range of emotions experienced when moving- rather than just the 'therapeutic' mobilities suggested by Gatrell (2013). Specifically, attending to the messiness of mobilities underscores the difficulty of equating particular mobilities with particular emotions.

Firstly, reference to Andrew's experience of using buses demonstrates the quite complicated decision- making process involved in making this particular form of mobility more tolerable. It is worth quoting Andrew at length here in order to show the high level of thought that goes into making any journey:

*Andrew: "I just live in a small village called [name of village], which is [a few miles] from the centre [of Durham] but it only takes about ten minutes on the bus, on a normal bus, you know? Obviously at peak working times it takes a little longer.*

*Lindsay: right*

*Andrew: ...it's only a ten minute route. It's not a long route but it's also [difficult] travelling by public transport... I'm much better if I'm with my support worker or if I'm with a family member, if I have to travel.*

*Lindsay: Uhu. Right, and do you decide to travel at particular times? For example, if the bus will be quieter?*

*Andrew: yes, yes I'm aware. If it's the school run...I try and avoid that...*

*Lindsay: yeh and when you're actually kind of thinking about getting on the bus and being on the bus, what kind of things are running through your mind usually?*

*Andrew: I just need to think that I have to get to this destination and I think that something really bad is going to happen but I don't know what [is going to happen]. I don't know what's going to happen... I feel very tense in my chest*

*Lindsay: right*

*Andrew: yeh*

*Lindsay: do you get pain and?*

*Andrew: into my shoulder as well, you know?*

*Lindsay: right*

*Andrew: and then walking on the bus... 'where do I actually sit?' You know, that can cause further anxiety Lindsay, you know?*

*Lindsay: so are there certain seats that you would prefer to sit on?*

*Andrew: I need, I need- really- to get to the beginning of the bus*

*Lindsay: uhu*

*Andrew: the longer I walk up the bus the more anxious I become*

*Lindsay: right. And if there's a situation where there's somebody else sitting at the seat you would like to go in what are you... [going to do]?*

*Andrew: I am reluctant but I know I have to continue and get on the bus, even with increased anxiety*

*Lindsay: uhu*

*Andrew: you know?*

*Lindsay: yeh*

*Andrew: but it's learning how to control that anxiety at this moment, you know?*

*Lindsay: mm. And do you find that the more times you're using public transport... is it the same every time? Does your anxiety reduce over time about it?*

*Andrew: it depends on a daily basis*

*Lindsay: yeh*

*Andrew: it can really fluctuate so it's [either] really massive or I can say it's- like- at a level that I would like say is like medium*

*Lindsay: yes*

*Andrew: you know, the only way I manage it better is out of peak times*

*Lindsay: yes*

*Andrew: as a general rule I manage better but still with social anxiety out of the peak times... [be]cause the bus is full- people are standing, you know? It's when I see the bus approaching, I'm going to think that I'm going slur my speech. Am I going to give him the right money? Am I going to drop my money?*

*Lindsay: uhu*

*Andrew: that's what is going through [my] head all the time. It sounds stupid, doesn't it?*

*Lindsay: no I don't think so. I think a lot of people have anxieties over different things."*

Andrew's account of bus travel is one in which he is constantly making decisions in order to try to reduce his anxiety- be that by travelling off- peak or sitting at the front of the bus. Thinking about this quotation as a whole, I am struck by the extent to which decisions that may appear as minor to some people (such as paying the bus driver) are thought- out in considerable depth. But Andrew also thinks that these anxieties must sound 'stupid'. When he asked me my thoughts on the extent of the 'stupidity' of being anxious about his interactions with the bus driver, I again realised that the dominance of some mobility experiences (for example, the idea that it is easy to travel to a nearby town by bus) mean that particular mobility experiences of 'others' are often dismissed as unimportant or even ridiculous. Indeed, perhaps he thought I would dismiss his experience.

Even the argument presented in this section is bound up with ideas about the normality of particular mobilities. I suggest that people negotiating multiple illness and/ or disability identities (certainly those who participated in this research) have to become acutely aware of their surroundings in order to develop coping mechanisms to improve their experience of public transport. But of course this assumes both a dominant mobility norm which needs to be constantly grappled with and also society's quite poor knowledge about the complexity of

'different' mobilities. Rather than using Andrew's experience to reinforce the dominance of normal ways of moving, I prefer to see it as demonstrating the very complex and messy 'alternative' mobilities that it is helpful to have more awareness of. This awareness helps to undermine the idea that just because it might be easy for one person to move in a particular way; it is not necessarily easy for the next person. Indeed, we are far from 'billiard balls' (Law 1999) travelling through space.

Andrew's suggestion that his experience of travelling by bus might sound stupid can be understood as a reflection of the social unacceptability of particular mobilities and mobility experiences. The negative emotional implications of having different mobility experiences are consistent with a society in which mental illness and disability are stigmatised. For example, in McKeever *et al.*'s (2003) research about the performance of motherhood amongst women using scooters or wheelchairs in a large Canadian city, one woman noted that health care professionals expressed concern that her child was not developing well because she was not able to walk alongside him. Clearly, this concern is premised on the idea that mothers are expected to move in particular ways and any deviation from this norm is met with scrutiny.

Andrew's experience highlights that the 'management' of anxiety when using public transport takes place in the context of diverging from accepted, dominant forms and experiences of mobility. The quite detailed quotation from Andrew's interview demonstrates the multi-layered decision making process that he goes through when taking a journey from home to the nearest town. In providing and analysing this example I have demonstrated the importance of paying attention to 'alternative' mobility experiences, which are often silenced or dismissed as inconsequential in the context of academic research on public transport focusing on how to get people from 'A to B' in the most efficient possible way (Cresswell 2011a).

Such mobility experiences are also highly relational. As Carolyn demonstrates, addressing the needs associated with negotiating multiple illnesses and/ or disabilities means interaction with other bodies:

*Lindsay: "how do you find bus journeys?"*

*Carolyn: eh... it's not too bad as long as I can sit- I always have to sit near the front in the bus which is unusual because there's people behind me [reference to earlier part of the interview in which she says she likes to sit at the back] but- em- I cope with it. You know,*

*because I don't want to be stuck at home on [my] own*

*Lindsay: uhu*

*Carolyn: em*

*Lindsay: do you ever kind of change where you sit? because I'm aware that some buses have those seats that you could sit- like- side on...*

*Carolyn: mm*

*Lindsay: do you ever do that...?*

*Carolyn: no I have to sit, I have to sit in the first full seat*

*Lindsay: right yeh, yeh*

*Carolyn: and if there's somebody sitting in my seat... I find that quite anxious. You know, it's like 'oh no somebody's sitting in my seat, what's going to happen now?'*

*Lindsay: and what about if a bus comes that's really full? do you ever wonder whether you're going to get on it?... because I'm just aware that sometimes there'll be no seats and maybe the only seat is at the back*

*Carolyn: well our local bus is never busy*

*Lindsay: ok*

*Carolyn: so that's not really something I've had to... confront. Em I think I would be very anxious if it was a busy bus and if somebody's sitting near the front sometimes I will ask, ask to sit where they're sitting*

*Lindsay: right, right*

*Carolyn: doesn't always work!*

*Lindsay: mm. I think, so in terms of you wanting to sit- or needing to sit near the front- do you*

*think that's equally both because of the difficulty walking or because of the agoraphobia or do you think it's just the agoraphobia?*

*Carolyn: it's a bit of both*

*Lindsay: a bit of both.*

*Carolyn: when you walk with a stick people are usually- quite em- I don't know what the word is [pauses] 'caring' I suppose.*

*Lindsay: mm*

*Carolyn: but em*

*Lindsay: I suppose though in the case [several years ago] and maybe you didn't have a stick, maybe you would still want to sit in that seat?*

*Carolyn: yes. but people can't see [that you have agoraphobia]*

*Lindsay: no. How did that work?*

*Carolyn: well, having something like agoraphobia and depression- they're like hidden disabilities and you appear normal to other people em and I'm not saying that having mental illness is abnormal; it's just that people don't know. Whereas with a stick it's like an outward sign that you've got some problems*

*Lindsay: mm*

*Carolyn: and em I'm trying to think back. It em- it was very- it could be very difficult getting on a bus when I was fully able*

*Lindsay: uhu*

*Carolyn: em I've always had to sit near the front."*

Although there are several interesting themes evident from Carolyn's account of bus travel, I'm particularly interested in how her experiences of multiple illnesses and/ or disabilities are

shaped when travelling *alongside* other people. In that sense, using *public* transport necessarily involves being with other bodies whilst mobile. As Carolyn demonstrates, the messiness of mobilities is a result of the relationality of mobilities. Indeed, Carolyn's ability to access the first 'full seat' on the bus is dependent on decisions made by other people about where to sit. But these decisions take place in the context of the acceptability of particular bodies occupying particular spaces.

Carolyn notes that before she used a walking stick it was difficult to access her desired seat, despite her requiring this accommodation because of her experience of agoraphobia. Her phrasing is really interesting here as she notes that: "it could be very difficult getting on a bus when I was fully able". This- apparently contradictory statement- can be understood in terms on the distinction Carolyn makes between her physical, visible disability (having difficulty walking) and her invisible mental illnesses (in this instance, referring to agoraphobia). So actually developing a visible disability alongside an invisible mental illness now means that she feels more able to access her desired seat on the bus.

Carolyn describes this as a reflection of the 'care' people feel towards people with visible disabilities. This care is theorised by Lawson (2007) in two possible ways. Firstly, she suggests that care could be understood in neoliberal terms as a private affair, occurring in homes and families. Under this construction of care, particular groups are dependent on others. For example, the elderly are dependent on the young and the disabled are dependent on people without disabilities. A second understanding of the concept of care is considered in terms of 'care ethics' in which we acknowledge the interdependence and relationality of care whilst also paying attention to the particular structures (for example, neoliberalism and masculinism) that have produced problematic imaginations of care (Lawson 2007). The care described by Carolyn could be theorised in either way, but crucially she felt it in a positive way. Indeed, as Staeheli and Lawson (2005) (cited in Lawson (2007)) argue, one aspect of care ethics is about the production of relationships that improve wellbeing. In this instance it seems like Carolyn's wellbeing was improved, although we don't know about the other people involved in the interactions.

But equally the interrelationships with other bodies are not always positive and may prove problematic for mobilities. For example, in Segrott and Doel's (2004) research about OCD, they note that the experience of a participant called Jane was made difficult when travelling by bus. They state that:

“The boundaries of the self are under perpetual threat from outside forces and must be constantly monitored and maintained. Jane was intensely distressed by being forced into physical contact with other bodies, coats, bags and exhalations whilst travelling on a crowded bus...” (Segrott and Doel 2004: 602)

This quotation indicates the importance for Jane of maintaining a barrier between herself and others in order to cope with being on a bus. Jane’s experience seems to point to both the disabling nature of bus travel, but also that her illness is more acute in particular places and times and produced in relation to the proximity of other bodies. Already there has been interesting work about how the skin is thought to work as a threshold between what is inside and outside of a person (Ahmed 2000). In relation to OCD, as indicated by Jane in Segrott and Doel’s (2004) article, the skin becomes the site where the self must literally be protected from the other. This example underscores the importance of relational bodily experiences in the performance of OCD.

Furthermore, the messiness of Carolyn’s mobility experience stems from the problematic distinction made between invisible chronic illnesses (including mental illnesses) and visible disabilities. Indeed, reflection on Carolyn’s quotation provides an empirical example from this research to supplement the discussion provided in the literature review (*Chapter 2*) about the differences in the way in which chronic illness and disability can be understood. In that discussion I reflected on Thomson’s (1997) idea that people who may ‘pass as normal’ (because they have an invisible disability) have to continuously assess the benefits and costs of ‘coming out’ as disabled. Before Carolyn developed a visible disability, she says that during bus travel she found it difficult because people could not see that she has a disability (agoraphobia). However, on development of a visible disability, she now felt that the other passengers were more caring towards her. Again, this points to the dominance of the visual in the negotiations of multiple illnesses and/ or disabilities.

But significantly, through examination of Carolyn’s example, we are able to add to the existing literature by saying that actually her experience of developing a visible disability means that she is now able to access the resources required that she found it difficult to access when living with an invisible disability. Hence, having multiple illnesses and/ or disabilities changes her level of mobility in this particular context. In the particular context of bus travel, use of walking stick actually enables her to access resources that help with her invisible disability of agoraphobia. Hence, her mobility experience is relational to other people but also to what else is going on in her body.



This section has sought to illustrate the ways in which people try to 'manage' their experiences of multiple illnesses and/ or disabilities on public transport. Not only do people go through very intricate decision- making processes about how their public transport mobilities can be made more tolerable, but participants expressed the variabilities associated with travelling alongside other bodies. Thus, the messiness of mobilities discussed in this research is a reflection of the messiness of both participants own bodies and the bodies of people that they travel alongside.

## 6.5 Transgressing socially acceptable and expected mobilities

But whilst this messiness is evident, this research also demonstrates that there is sometimes a desire among participants to resist or deny the alternative mobilities described in the previous two sections. It will be suggested in this final section of the chapter that this resistance or denial is a result of the stigmatisation of illness and disability, the desire of participants to be 'normal' and- also- just an aspiration to live their lives in a way that means they can undertake desired mobilities and activities.

Negotiating the possible and necessary mobilities and movements associated with living with multiple illnesses and/ or disabilities takes place in the context of the social acceptability of particular movements and mobilities. For example, Vicky describes the difficulty associated with not conforming to expected movement behaviours:

*Vicky: "... I remember... waking up- it would take me half an hour to wake up properly and then half an hour before I could bring myself to get out of bed and- em- that was partly [because of] lack of energy and partly [because I] just didn't want to get up, didn't want to have to eat that day, didn't want to have to- And I think the other thing that made a massive impact... was that you couldn't do these things in private. ... [because of living in university halls of residence]. I remember one of my behaviours was that I felt like the tables and the trays were unclean so every day I'd have to find a way [to avoid tables and trays]... So everyone else would have their plates on the tables and I'd be sat there eating off my lap and if you've got something covered in gravy it's such a nightmare. People would actually say to me 'why are you doing that?' ... [also] like if James [her partner who also has OCD] was in the loo washing his hands and he's been there for- like- four minutes and somebody's been in... then left again... I think that's one of the most tiring things about it... I almost felt like if I could perform all my behaviours on my own [with] no- one there to judge me it would be absolutely fine... so you've got a level of anxiety and you've also got embarrassment... I*

*felt ashamed of the things I was doing which meant I was more anxious and dependent on them [the routines].”*

The final couple of sentences of this quotation highlight that moving in different ways to what other people expect makes living with multiple illnesses and/ or disabilities even more difficult than the experiences of the bodily symptoms for Vicky. Indeed, she notes that if it were not for the judgement associated with moving in alternative ways then ‘it would be absolutely fine’. Hence, it is evident that stigma plays a big part in how people feel and experience mobilities when negotiating multiple illnesses and/ or disabilities.

This stigma felt is hardly surprising given the way in which illness and disability have been portrayed in the media in recent years. In Briant *et al.*'s (2013) research, the authors note that when they asked people in the UK what a newspaper story featuring disability would be about, the most frequently cited answer was ‘fraud and benefit cheating’. In the aftermath of the 2007/ 08 financial crisis in the UK, disability was reported about in 2010/11 in a much more negative way than in 2004/ 05 (Briant *et al.* 2013). Although there are many reasons for the stigmatisation of (especially) particular illnesses and/ or disabilities, this shift in press coverage of disability makes it problematic to move in ways that may indicate a form of bodily difference to the societal norm. So the messiness of Vicky's mobility is a reflection of the stigmatisation of particular bodily movements.

Additionally, these ‘alternative’ mobilities mean that desired mobilities and immobilities are difficult to achieve, despite having positive impacts on *some* aspects of wellbeing. For example, Andrew states that although he used to be able to attend classes at Waddington Street Centre that aim to improve mental health (for example, illustration and animation, psychology and creative writing classes) moving in ways that allow him to participate in these classes has now become difficult:

*Andrew: “...I'm in constant [physical] pain, it affects my mobility. How can I sit for any length of time? How can I be mobile for any length of time- you know? I'm receiving treatment for that at the moment with pain killers.*

#### *LATER IN THE INTERVIEW*

*Lindsay: ... and do you... go to some of the classes here?*

*Andrew: I did used to... but I have to sit for two hours... and I can't sit for two hours with my*

*[physical pain]. I need to get up. I need to get up. You know, it's... I feel enclosed in... the classrooms.*

*Lindsay: so it's sort of the pain of sitting for a while coupled with [feeling closed in]."*

Andrew's experience shows that participating in mobilities that he is expected to be able to, and that he used to be able to participate in, are very difficult. Interestingly, he notes the problematic nature of being mobile and being immobile for what he would see as extended periods of time. This presents such a quandary because although attending a class could improve his mental wellbeing, any gathering that expects bodies to be either mobile or immobile for a significant period of time has become difficult. Indeed, Andrew's example highlights that the messiness of mobilities lies in deviations from socially expected mobilities and immobilities. Norms about how people should behave and move in classroom settings, specifically- conventions of everyone in the class moving in quite similar ways at similar times, results in the restriction of access for differently mobile bodies.

Hence, despite a desire to take part in activities that might improve quality of life and wellbeing, this is sometimes not possible because of both the expected and accepted mobilities in particular contexts. The quotation from Andrew communicates the subtleties of *expected* movements within classroom settings and how this limits his participation, whilst the quotation from Vicky highlights the *accepted* mobilities in a communal dining room and how alternative mobilities to the norm are questioned by others. Crucially, the messiness of mobilities may be resisted or denied in particular situations because of a desire to live life in a particular way (consistent with societal norms) or because of the stigma associated with unacceptable mobilities.

This final section contributes to the overall argument presented in this chapter that the mobilities of people living with multiple illnesses and/ or disabilities are messy. This messiness of mobilities can be understood as a reflection of the messiness of emotional, fluid and unpredictable bodies in the context of constantly (re) negotiating stigma and societal expectations. This chapter was partially written as a response to Andrews *et al.*'s (2012) suggestion that researchers should consider the complexity of movement experiences (including amongst people with chronic illnesses and/ or disabilities), undermining the idea that we all move in neatly predictable and 'rational' ways. In doing so, the experiences of participants in this research have shown the ways in which achieving desired mobilities and moving in expected ways is often fraught with difficulty.

## Chapter 7: Hopelessness

### 7.1 Mark's diary

*My life has been filled with misery, really. I am writing about this misery because my counsellor said that sometimes it can help. Although I am sceptical about the value of writing about my experiences, I suppose that if I write then I can at least show my counsellor that I'm willing to try what she suggests. She said I should try and write a 'reflective diary', based on my experiences each day. So here goes...*

#### Thursday 1<sup>st</sup> January

*It is the start of another year and I know a lot of people try to make New Year's resolutions and plans for the year ahead but I'm just trying to focus on getting through the day. I really don't want to think about the past or the future but I suppose it is inevitable at this time of year. It is a really bad time for me because we are approaching the two year anniversary of my very first suicide attempt. It was at the beginning of January- I can't remember the exact date- that I went to the Tyne Bridge with the intention of jumping off. I had drunk quite a lot of whisky and vodka beforehand in order that I would be gutsy enough to go through with the jump. At that time of my life I was drinking a lot anyway so the beginning of that night was not very different to most other nights.*

*Anyway, I got to the bridge and just sat there thinking about everything that had gone wrong in my life. But I didn't jump in the end. I was so annoyed that I didn't have the courage to jump and when I got home I realised that all my pain would have ended if I had just been more courageous. At that point I was still heavily intoxicated and decided to just take whatever pills that were available in my house- I think that included ibuprofen, sleeping pills and some pills I take for other problems that I have. I didn't have very many pills in the house at that time but I really thought that the cocktail of alcohol and pills would mean that I could just try and go to sleep and then I would never wake up again. When I woke up the next day I was so disappointed with how everything had gone and I basically didn't leave my flat for about three weeks. At this time of year I always think that if I had succeeded with committing suicide then I wouldn't be in pain anymore. But anyway, I just need to try and put all that to the back of my mind. If I get through today then I will see my sister tomorrow- that is something I can look forward to.*

#### Friday 2<sup>nd</sup> January

*I was supposed to meet my sister in town today but I didn't feel up to it so just sent a text to say that my neck has been giving me bother again. It is true that my neck is sore but I suppose I could have gone to meet my sister if I had made more of an effort. I feel really guilty about not going because she is not able to get very much time off work and she has two kids to look after as well.*

*I don't know what I would do without my sister because she has given me a lot of support over the years. I just don't know how I would cope without her. The problem is that things are only going to get worse. When I was younger I could make friends quite easily but now I can't do that. I tend to avoid most social situations now and, because of that, I can really only rely on my mother and sister. There is no- one else. But I'm just dreading them dying because I'd be left completely alone. I just hope that, somehow, I die before them. It does give me comfort to know that I could try to kill myself at any time though, so if things ever get really bad then I have that option. People hate hearing me say that having the option to kill myself gives me comfort but it does and this is my diary so I can write whatever I want here.*

*But in the meantime, I hope my sister doesn't mind too much about me cancelling today's meeting. I bet she is secretly annoyed but she would never say anything about it or fall out with me because of it. I might try and give her a phone next week but I'll probably just watch TV, drink and sleep this weekend though.*

#### Sunday 4<sup>th</sup> January

*I'm feeling low today because yesterday I suddenly remembered that I've got to go to the job centre tomorrow. I hate going there. I don't want to write in the diary anymore today.*

#### Tuesday 6<sup>th</sup> January

*I made it to the job centre yesterday. The person I was meeting with was quite nice but she is always talking about the 'pathway to work'. They sort of understand that I can't work at the moment but they also put pressure on me to do things that might help with getting a job in the future. For example, they wanted me to do a one week I.T. course but I didn't want to because I hate social situations. I also don't imagine that being in a room with a load of other unemployed people would be very motivating either!*

*In the past I was able to contribute to society. Before I had my accident in the warehouse I was working around 45 hours per week and had a good social life, an OK ish flat and the ability to go on fairly nice holidays. But after damaging my neck and arm in a warehouse accident, I just can't do that type of work anymore. I keep thinking that I should have really pushed for compensation but I didn't want to deal with all the forms and lawyers. I did lose everything after the accident and now I have to scrimp and save just to get by. And if you*

*don't have money you can do hardly anything. You don't have much control over your life either. I have to rely on other people for everything. I want to be more independent but I don't think it will get any better in the future.*

*I'm not sure if I will ever be able to work again and I always worry that even if I do get a job; I won't be able to cope and then I'll have to leave. That will leave me without any income for a while because it can take a long time to get benefits claims forms processed. At least, at the moment, I now have everything set up. If there is a change then I might be without any income for a long period of time. So I know that the person I saw in the job centre today does mean well but going there just makes me worry about the future so much. I can only see that my finances are going to become more stretched. Everything is getting more expensive as well. They keep saying on the news that the economy is getting better but, if it is, I certainly haven't noticed it.*

### Wednesday 7<sup>th</sup> January

*Today I went to an art class at a nearby mental health day centre. Although I have problems with my neck and arm, I'm still able to draw and paint with my other hand. I really enjoy going to that class because I can just forget about all of my problems for an hour or so. Today I painted a picture of a beach and lighthouse that I used to really enjoy going to when I was a teenager. At that time I was such a positive person (and I took it for granted that I would always be pretty happy and hopeful) but now I'm so negative about the present and the future.*

*Trying to develop hobbies, such as art, does help with improving wellbeing but most of the time I just don't feel up to being in social situations. It is very hard to 'think positively' when you have clinical depression! On top of that, the pain in my neck and arm is always going to be present in my life so thinking about the future only brings misery. I sometimes think of things that I want to do, such as travelling or having a family but then it is so painful when you remember that it will not happen. It is best not to try to hope for anything because then you reduce your disappointment when it does not happen.*

*That said, I think that keeping a diary over the last week has helped to improve my state of mind. I don't know if that would happen over the long-term though. I'm going to let my counsellor know that the diary is sort of working alright. I know there are no magic bullets to improving my wellbeing but if I can try to 'live in the moment' a bit more then at least I would be able to stop thinking about the misery that is coming my way in the future.*

## 7.2 Living with hopelessness

Mark's diary communicates the multiple layers, scales and contexts in which hope and hopelessness become significant aspects of his life. Specifically, I created this piece of ethnographic fiction to demonstrate the many and various implications of living a life at odds with dominant narratives of progress that are premised upon and reproduce 'the promise of happiness' (Ahmed 2010). In Ahmed's (2010) book, it is argued that happiness is typically positioned as an object that human beings *are* universally (or at least, *should be*) working towards. However, just as the previous two chapters have emphasised the ways in which people participating in this PhD research do not 'fit' into common models of diagnosis, treatment and mobilities that assume a particular set of bodily features and capacities (see *chapters 5 and 6* for a detailed account of these); so too are the experiences of people negotiating multiple illnesses and /or disabilities at odds with idealised conceptions of 'the future'.

Indeed, although some participants did express hope about some aspects of their future lives, key feelings discussed by all of the participants in this research included: disappointment, failure, uncertainty and hopelessness. Crucially, futures were typically imagined by many participants as without the *possibility* of positive change. Focusing on these 'pessimistic' narratives is not intended to negate the positive aspects of life that people discussed in this research, but rather to explore the implications of living with the (often) all-encompassing hopelessness that is typically deemed 'too negative' or 'too distressing' to be heard. In that respect, the relationality of narratives of happiness becomes important. Attaining happiness is- for some- predicated upon ignoring or dismissing anything and anyone that is perceived as a threat to the pursuit of the positive and fulfilling lives that 'everyone' wants to lead (Ahmed 2010). But by paying attention to 'unhappiness- causes' (Ahmed 2010), such as in relation to the experiences of people negotiating multiple illnesses and/ or disabilities, the voices of previously silenced people are heard and the instability of narratives of progress is exposed.

Imaginations of futures necessarily involve *some uncertainty* about the lives our future selves will lead. However, in the context of this research, uncertainty is understood by participants as almost exclusively negative. In that sense, the expression of feelings of *uncertainty* about the future was almost always accompanied by feelings of *certainty* that those futures *could* be difficult, painful and stressful. Therefore, negotiating multiple illnesses and/ or disabilities is, for many people, also about trying to live a life that is imagined as only getting worse over time. This idea of deterioration will be explored in this chapter in relation to three important aspects of life: money, health and relationships. Importantly, however, it is

the multiple layers of hopelessness, operating across many parts of life that will serve to highlight the ways in which people participating in this research do not 'fit into' dominant narratives of happiness and hopefulness.

### 7.3 Narratives of hopelessness

In paying attention to the narratives voiced by participants in this research, we become aware of how "dominant cultural scripts" (Dias 2013: 31) of bodies are imagined, reconstructed, promoted and undermined. Through analysis of narratives we are further able to explore how people theorise and communicate knowledge about their lives (Dias 2013). In the context of this chapter, focusing on narratives of hopelessness also enables an examination of how people negotiating multiple illnesses and/ or disabilities situate their future lives in relation to their past and present experiences. Although listening to the voices of people expressing 'bad' emotions about the future may be difficult for some people to hear (Wilkinson and Kitzinger 2000), it was an important theme discussed by research participants and exploration of it yields interesting insights about the concepts of hope, time and futures.

Specifically, the narratives presented in the subsequent sections of this chapter destabilise notions of time that privilege the pursuit of progress. The participants in this research who negotiate multiple illnesses and/ or disabilities typically do not view their lives in terms of a linear movement from a less developed past towards a more successful future (Milojević 2008). But the emotional and social cost of challenging this narrative of progress is high. In a society that associates 'getting well' or 'overcoming disability' with progress, it is unpopular to 'think negatively' about the *already* 'negative' emotions associated with illness and disability- such as: pain, unhappiness and loss.

In relation to ill and disabled bodies, narratives of progress are tied up with a moral obligation to 'be positive'. This obligation to be positive is evident from the language used to narrate illness and disability experiences. For example, in recent years there has been a movement towards thinking of people who have been successfully treated for cancer as empowered and brave 'cancer survivors' instead of 'victims' (Atkinson and Rubinelli 2012). Whilst this imperative to 'be positive' may be voiced by people who live with (or have lived with) cancer, it is not always reflective of their internal emotional states (Wilkinson and Kitzinger 2000). In research with a group of breast cancer patients in the North of England, for example, talk of 'positive thinking' worked as a way to both contain and curtail 'negative' discussions as well as actually allowing 'negative' discussions to take place (Wilkinson and



Kitzinger 2000). Interestingly, some people used talk of 'positive thinking' as part of a strategy to present negative emotions in a more positive light, thus 'lightening the emotional load' for anyone listening (Wilkinson and Kitzinger 2000). In both instances, demonstrating 'positive thinking' is understood as a moral obligation for people living with cancer.

'Being positive' becomes particularly important for ill and disabled people in the context of close scrutiny about the causes of cancer, alongside other illnesses and disabilities. In recent history, significant attention has been placed on the factors that may influence the development of cancer in the body- such as smoking, lifestyle and dietary habits (Wilkinson and Kitzinger 2000). It is argued that the requirement to 'think positively' can help patients mitigate accusations that they may actually be to blame for the development of their cancer (for example, because they drank 'too much' or ate 'too many' high fat foods) (Wilkinson and Kitzinger 2000). Within this culture of blame, the imperative to 'think positively' becomes an important strategy in emphasising the morality of patients who may otherwise be condemned.

As well as linking the pressure to be happy and hopeful to narratives of progress and morality, it is also associated with neoliberal economics in which the promises of happiness and hope are bought and sold. Schoch (2006) explains that 'happiness' is a huge industry in which there is a marketplace for products, such as antidepressants and self- help books. Specifically, it is in the interest of these 'happiness industries' to promote the idea that everyone is 'entitled' to achieve happiness (Schoch 2006)- something that the rise of positive psychology has reproduced (Miller 2008). With positive psychology's focus on achieving goals, positive emotions (such as happiness and hopefulness) become associated with attaining particular products or lifestyles (such as having a fantastic house or being wealthy) (Miller 2008). Hence, narratives of happiness and hopefulness are not natural, universal or unproblematic- they are always intimately tied to particular notions of progress, morality and neoliberalism.

But participants in this research certainly challenge dominant conceptions of happiness and hopefulness. Indeed, how can we understand the experiences of participants who do not 'fit into' hegemonic narratives of hopefulness? Significantly, the narrative of hopelessness often presented by participants in this research does actually conform to one aspect of hegemonic time, that of: linearity. As shall be demonstrated in the subsequent sections of this chapter, people typically viewed the future as either: a) just as bad as the present or b) worse than the present. As Milojević (2008) suggests, this linear idea of deterioration is also dominant in our culture. Hence, although the narratives of futures presented by people negotiating multiple illnesses and/ or disabilities typically destabilise

hegemonic conceptions of time that privilege progress, morality and accumulation, these narratives also reproduce linear conceptions of time in some respects.

The prevalence of ideas of deterioration and decline in this research, I argue, firstly has to be understood within a social context in which illness and disability are typically considered as negative. In work by Thomson (2005), she writes that:

“... disability identity goes unclaimed by and unscribed to accomplished people. Because the identity ‘disabled’ acts as a disqualifier, it is often not associated with success or competence.” (Thomson 2005: 1561)

Although feminist disability scholars seek to promote interpretations of disability in terms of human variation, the ideas of ‘deficit’ and ‘failure’ are still typically associated with bodies that do not conform to normative expectations (Thomson 2005). The dominance of such problematic conceptions of disability mean that hopelessness becomes a key feature of the narratives presented in this research.

Secondly, it is important to consider broader temporal considerations that shape the development of hopelessness narratives. Following Grosz (2005), although the purpose of this chapter is to explore the imagined future selves discussed by research participants, this cannot be achieved in isolation from discussion of other temporal modalities. Whilst the relationship between pasts, presents and futures is not deterministic, these temporalities are interlaced together in the production of particular narratives (such as hopelessness). For the purposes of this chapter, I understand the relationality of these modalities with reference to the idea that:

“The future, as with the past, emerges as virtual; it is not inevitable but neither is it completely open.” (Coleman 2008: 99)

For example, the concept of duration is particularly important here. In Coleman’s (2008) work on ‘things that stay’, durations are understood as intense memories, understandings and imaginations of pasts which endure and are understood in both similar and different ways in relation to present and future temporalities. As will be demonstrated in the subsequent sections, the histories of participants in this research shape particular imaginations of (hopeless) futures.

Hence, narratives of hopelessness present a challenge to hegemonic conceptions of time that are premised upon the ideas of progress, morality and (within neoliberal contexts) accumulation. In presenting some of the narratives of hopelessness expressed by participants negotiating multiple illnesses and/ or disabilities, this chapter seeks to listen to the voices of those who do not ‘fit into’ the (happy, hopeful) imaginations of futures that are

typically reproduced in our society. Expressing hopelessness comes at a significant social price for participants in the context of dominant illness and disability narratives that privilege ideas of positivity and improvement. Specifically, I argue in this chapter, that this sense of hopelessness is situated within a social context in which any deviation from normative expectations of bodies is considered negatively. Additionally, through exploration of the heavily interlinked temporal modalities of pasts, presents and futures, we become aware of the relationality of hopelessness to particular life biographies, experiences and capacities.

## 7.4 Money, work and benefits

In the process of narrating their imagined futures, participants in this research frequently articulated a sense of hopelessness about their financial prospects. Relating back to Grosz's (2005) work, this particular imagination of the future has to be understood in relation to other temporal modalities. As such, this section about money will focus on the ways in which one participant's imaginations of money and the future (including its obviously close links to issues of employment and claiming government benefits) are shaped by memories of her own life experiences. By focusing on some of the data generated during an interview with Anna, the multi- various aspects of financial difficulty that she articulates become situated within broader landscapes of hopelessness.

The implications of financial struggle for people negotiating multiple illnesses and/ or disabilities cannot be underestimated. As Wendell (1996) explains, poverty is an important form of disablement experienced by people whose bodies differ from societal 'norms':

"Poverty is the single most disabling social circumstance for people with disabilities, since it means that they can barely afford the things that are necessities for non- disabled people, much less the personal care, medicines, and technological aids they may need to live decent lives outside the institutions, or the training or education or transportation or clothing that might enable them to work or to participate more fully in public life." (Wendell 1996: 41)

Without access to adequate money and resources, the lives of people with disabilities are made more difficult. The articulation of feelings of hopelessness about imagined financial futures was, in the case of Anna, heavily influenced by her past and presents struggles. In this section, three segments from my interview with Anna will be considered in turn in order to demonstrate the ways in which narratives of hopelessness emerge from concerns about the financial implications of bodily variabilities, the structures of employment and the politics of accessing financial resources from the government.

Maintaining a decent standard of living is dependent upon societal attitudes towards the expected functions and capabilities of bodies- including the extent to which bodily variabilities are 'accommodated' in various contexts. However, as Anna's experience highlights, variabilities of bodily capacities often do not 'fit into' accepted distinctions made between ability/ disability and health/ illness:

*"Anna: "I don't actually get DLA [Disability Living Allowance- a government benefit] at the moment. Em, I'm just going onto 'employment support allowance' [another government benefit] but, obviously, the longer I'm on it; the more likely I am to have an assessment. And I think, because I'm actually physically able to walk and stuff like that, I think they are just going to say... 'you're fit for work'. Em, but in my experience- when I've been this bad in the past; I'm not fit for work. I may have a few good days where I can go in, I can get on with my work. But all of a sudden I kind of almost flip out, you know? And it's like 'no can't do this no more'. And I'm in tears and I'm getting angry and agitated and anxious... what employer wants that? Do you know what I mean? I mean, I know a lot of them are getting really good when it comes to disabilities and mental health and stuff like that. But at the same time, especially in today's job market, if you've got a choice between somebody with mental health issues and somebody who is perfectly well and- you know, fit and healthy- then they're going to take somebody who is fit and health, really. They can afford to pick and choose. But the government doesn't seem to look at that side of things. You know, it's like: 'well if you can physically do this or you can physically do that then you can go to work.' But they don't seem to take into account, you know, what it's like on a bad day."*

As this quotation shows, Anna's experiences of bodily variability mean that she is concerned about her present and future employment prospects. Specifically, she explains that, although she may be able to work for some of the time, at other times she may not be able to. For Anna, living with multiple mental health problems means being *uncertain* over how she may 'fit into' a work environment that typically requires a standardisation of bodily functions and capabilities. In this instance, being *uncertain* about her bodily capacities brings concern about the extent to which an employer would view her as an acceptable worker, particularly in a difficult economic climate.

The key worry, for Anna and others, is that bodily variabilities- by definition- cannot be easily fixed and categorised, thus leading to difficulties in either accessing government benefits or employment. Whilst Anna expresses worry that those assessing benefit claims don't take into account 'what it's like on a bad day'; she also expresses concern that employers will *only* take into account what she is like on a bad day. This double bind means

that accessing the necessary financial resources to maintain a decent standard of living is difficult.

Such difficulties related to the categorisations of bodily variabilities mean that many people negotiating multiple illnesses and/ or disabilities feel a sense of hopelessness about their financial presents and futures. Indeed, how is it possible to be hopeful about the future when bodily variabilities make it difficult to 'fit into' either employment or benefit claiming contexts? Pinder (1996) explains that our institutions work with the intention of achieving simplicity and clarity: requiring people to be "either sick or fit" (Pinder 1996: 136) (original emphasis). But, as has been demonstrated in the case of Anna, this binary thinking means that some people's bodily variabilities do not 'fit in' anywhere.

Additionally, the classification of people's experiences of bodily variabilities into either 'good days' or 'bad days' is problematic. In research with people living with physical disabilities in Toronto, Canada, Lightman *et al.* (2009) challenge the dominance of such dichotomous accounts of bodily variabilities. They write that:

"... a view in which individuals are either revitalized and able to live up to able-bodied expectations of appearance and performance on a good day or are worn-out, and incapable of meeting hetero-normative expectations of able bodies on a bad day merely resuscitates monolithic notions of embodied identity." (Lightman *et al.* 2009)

Clearly, bodily variabilities cannot always be correlated with 'good days' and 'bad days'- not least because of the pace at which bodies can change. In the case of Anna, for example, she notes that: '...all of a sudden I kind of almost flip out' (see above). Such temporalities of bodily change are important here- the 'day' is not always the temporal interval at which variabilities occur. The fluid and uncertain bodily experiences of participants such as Anna demonstrate the difficulty that those living with multiple illnesses and/ or disabilities have in 'fitting into' accepted temporal structures (exemplified here in relation to the 'day', but could also extend to conceptions of the 'working week' and 'being on time') shaping access to both government benefits and employment. Hence, narratives of hopelessness about money are articulated in relation to an awareness of the 'double bind' that people living with bodily variabilities face. Maintaining a decent standard of living is achieved through access to adequate financial resources but such access to either government benefits or employment is shaped by fixed, dichotomous institutional conceptions of disability that result in the exclusion of people with multiple, changing and complex illnesses and/ or disabilities from both settings.

Building on this discussion, the structures of employment are certainly an important feature of the narratives of hopelessness presented by participants in this research. The idealisation

of particular workers and particular working styles leads to the physical, social and emotional exclusion of people whose bodies 'contravene' expected norms. Continuing with reference to the experiences of Anna, employment structures influence where and how she can work:

*Anna: "...I left [my last job] because I hurt my back. I was working in a shop, so there was a lot of heavy lifting and stuff. But, yeh, I was [also] in an office over in [name of place in the United Kingdom] and I wasn't technically employed. It was an employment training scheme- so it was a work situation. I was in a working office, em, but I actually did that. I was fine for a few months and then all of a sudden it was like the pressure just got to me, you know? Em, I don't know why. I suppose it was because I'd been there [for] a while and I knew it wasn't going to last forever and I knew I was going to have to go and get a job. My anxiety just took over and one day I just flipped and I lost my temper with people around me and I got up and I just walked out and one of my supervisors came running down the street after me and she was like 'what on earth was all that about?'. And I just burst into floods of tears..."*

Significantly, Anna firstly describes working in a shop but then having to leave her job after hurting her back. However, moving into an office environment was still difficult to manage because of her anxiety. It is unclear whether continuing to work in the shop would have meant that Anna's anxiety was more manageable, but it is clear that the combination of both back problems and mental health problems influenced the types of environments in which she could work in. From this quotation, there is one key question that I would like to address: what is it about the structures of employment that Anna found difficult to negotiate?

Capitalist economic structures typically require the standardisation of tasks (and bodies), to the detriment of those who do not 'fit into' accepted, pre-existing conceptions of the 'ideal' body. In the case of Anna, such standardisation may seem quite innocuous- with examples including the twin expectations that everyone can handle a certain amount of pressure and a certain level of uncertainty related to working on defined- period contracts and projects. These 'subtleties' of our capitalist economic structure are reproduced by common disembodied and standardised workplace practices.

For example, 'standard jobs' are typically 'scientifically' and 'objectively' designed to include the requirement that a broad range of tasks are performed to the expected level (Foster and Wass 2013). This, firstly, means that a person living with types/s of illness and/ or disability that limits the ability to fulfil *one* aspect of the job description becomes unsuitable for the *entire* job (Foster and Wass 2013). Secondly, the expected standardisation of work roles and bodies means that the power structures that lead to the exclusion of particular

bodies from particular workplaces go unchallenged (Russell 2002) because of the perceived neutrality and objectivity of such practices (Foster and Wass 2013). Indeed, Russell (2002) goes as far to argue that the creation of 'the disabled body' itself enables the (re) production of a capitalist economic model that places wealth and power in the hands of a few (typically white, middle- class and able- bodied men) by subjugating the value of 'other' bodies.

This issue is compounded by the ever- changing expectations about what it is 'possible' and 'reasonable' to expect of bodies. In the U.K. context, the financial crisis (beginning in 2008) prompted the Conservative- Liberal Democrat coalition government to argue for and implement reductions to the funding of the public sector (Harwood 2014). However, there is concern that these reductions in funding have negatively affected disabled workers (alongside other groups of people). For instance, in research conducted with employees, managers and others at 33 local authorities, four human resources managers stated that some adjustments to working conditions to enable access for people with disabilities were no longer considered 'reasonable' (Harwood 2014). What is considered a 'reasonable' adjustment, then, has changed as a result of the current political and economic climate. Employment structures are thus based on a presumption of standardised bodily capacities, but what is considered as 'standard' is subject to change. These capitalist employment structures leave people, such as Anna, sometimes unable to meet employers' requirements. Such a narrative about negotiating work expectations is, understandably, steeped in a sense of hopelessness about her present and future circumstances. Indeed, when Anna asks 'what employer wants that?' (in relation to her being angry, agitated and in tears) in the first quotation of this section, she is also asking 'Who would employ someone with my multiply ill and disabled body?'

Reflecting on this question provokes consideration of the extent to which participants in this research felt accommodated when seeking financial assistance in the form of government benefits, given the difficulties associated with accessing employment. But, as shall be demonstrated, this articulation of hopelessness also extends to the processes involved in applying for financial assistance from the government. In the third and final quotation from Anna in this section, she narrates the quandary she faces in negotiating the benefits application system:

*Anna: "... when my doctor first gave me my sick note for my depression and anxiety, I know for a fact I should have taken it straight down to the dole [government benefits application office] and said 'I've got to go on the sick'. But I actually took a week out to consider whether I wanted to do it or not because I know what I'm going to face. I know I'm*

*going to have to face my medical assessment and I know it means a change in benefits. So we've got to reapply for housing benefit and all that sort of stuff and the anxiety was: 'well, what happens if we miss a week's money?' You know, if they're late sending us it we're going to be screwed for the rent and stuff like that. Em, and it does affect me really badly. In a way I would rather have stayed on job seekers' [allowance] because all the benefits were there, they were in place, they were claimed. But at the same time that means I've got to go and look for work which I know I'm not ready to take on, you know? So it's like 'well what do I do?' ... so yeh I do get very, very anxious about what's going to happen in the future but as a result of that I have to try and focus on today. I have to try and not let myself think about what's going to happen tomorrow because otherwise I wouldn't leave the house."*

Anna's experience of deciding whether or not to apply for government benefits is characterised by both a feeling of uncertainty over what the future will hold and a feeling of certainty that the future will be difficult. Importantly, Anna's anxiety is based on previous experiences of trying to access government benefits: tellingly, she notes that: 'I know what I'm going to face.' This is only exacerbated by the current political and economic climate in which the eligibility for receipt of benefits is being tightened. For example, before the coalition government came to power, people may have qualified for DLA (Disability Living Allowance) if their mobility was limited to under 200 metres (Cross 2013). Then the minister for disabled people, Esther McVey, proposed reducing this threshold to 50 metres before finally deciding that those who can walk more than 20 metres will not be entitled to DLA (Cross 2013).

This redrawing of the thresholds between ability/ disability and health/ illness epitomises the politics of accessing government benefits. Interestingly, changes to the ways in which bodily variabilities become categorised in the context of access to government resources are similar to the changes previously discussed in relation to access to 'reasonable' adjustments in the workplace (see Harwood (2014)). In both cases, being classified as 'disabled enough' to access specific resources is becoming more difficult. Again, this points to the double bind that people participating in this research face: it may be both too difficult to access employment and too difficult to access government benefits.

Piecing together the three quotations provided in this section from my interview with Anna tell a painful story. A narrative of hopelessness emerges from concerns about the financial implications of bodily variabilities, the structures of employment and the politics of accessing resources from the government. Again, the purpose of focusing on this issue is not to 'be negative' about the possible futures that participants in this research may experience; but



rather to explore the histories and contexts in which narratives of hopelessness are articulated. In this section about money, work and benefits I have sought to demonstrate that, for many people, living with multiple illnesses and/ or disabilities is accompanied by a sense that life is not going to get better over time. But this imagination of the (hopeless) future contradicts dominant narratives of progress and the pursuit of happiness. Presenting details of the imagined financial futures of participants in this research is just one way in which dominant imaginations of idealised, happy futures are destabilised- so too is it important to explore the other ways in which people participating in this research do not 'fit into' particular imaginations of the future.

## 7.5 Health futures

*Jack: "I've never had an experience of hearing voices but who knows if it might happen."*

As this quotation shows, Jack's imagination of his future body focuses on one way in which his health *could* deteriorate. Although Jack was not specifically asked about the issue of 'hearing voices', it is interesting that he mentioned this symptom when interviewed. So, what is it about past and present life experiences, understandings and relationships that has prompted participants, such as (but certainly not limited to) Jack, to imagine their future body as one which will become more ill; rather than more well? In this section, narratives of hopelessness about health are explored in relation to participants' past and present experiences of negotiating multiple illnesses and/ or disabilities.

It is important to mention here that such past and present experiences of illness and disability are not considered as deterministic of particular, imagined futures. Furthermore, although it is outwith the scope of this (fairly short) section to discuss the intersectionality of other imagined future bodily trajectories, these are still important. For example, in future research it could be fruitful to consider how imaginations of ageing bodies become intertwined with the narratives of hopelessness associated with negotiating multiple illnesses and/ or disabilities. As a starting point, this section offers an exploration of the imaginations of health futures narrated by research participants, as related to the important concepts of 'resilience' and 'self-care'.

Notions of 'resilience' and 'self-care' that dominate narratives of public health are distant from the imaginations of health futures provided by several of the participants in this research. Indeed, within some sections of public health discourse, the impetus for preventing

and managing illness is viewed as the responsibility of the individual (Fraser 2004). For example, injecting drug users are frequently blamed for a lack of progress in their treatment; without paying enough attention to the broader structures, practices and relationships that shape decisions around drug use (Fraser 2004). A further problem with this individualist approach to public health, as shall be demonstrated in relation to the accounts provided by Mark and Michael in this research, is that it is based upon people living with illnesses and/ or disabilities perceiving a 'healthier' future as both desirable and achievable.

In the context of negotiating multiple illnesses and/ or disabilities, the possibility of having developed 'yet another problem to add to the list' may not be met with a sense of urgency about being diagnosed and treated. This 'lack' of concern is evident from Mark's account of developing a new symptom:

*Mark: "Now, recently I've been having problems down below...and I'd say about a month ago- this is how depression and anxiety can make you think- I was passing blood*

*Lindsay: mm*

*Mark: nothing else, [just] blood. And I didn't care... I was so fed up, stressed, depressed...I just thought: 'if this is it; this is it'. I really, honestly, didn't care."*

This apathy that Mark felt, about what some may consider as a serious problem in need of attention, underscores the centrality of narratives of hopelessness to his present and future imaginations of health. As Mark explained, his experiences of anxiety and depression meant that he did not care what the passing of blood meant for him and, at that time, he did not view the prospect of his life ending as problematic. Importantly, Mark's reluctance to engage with medical systems in this instance is inseparable from the long, tiring and often frustrating experiences he has had with previous clinicians. This quotation highlights the point that actually having the will and capacity to seek medical advice about the development of new symptoms may become diminished if other illnesses and/ or disabilities are already being negotiated.

To some, Mark's lack of concern about this new symptom may be understood in terms of a 'lack' of health resilience. This concept is defined as the ability to, not only withstand adversity, but to become hardier because of a difficult experience (Goward *et al.* 2010). Viewing this concept through a geographical lens may mean working towards understanding the extent of 'health resilience' in particular places. Although health resilience is a difficult

term to pin- down, it has been used to research the health- related issues of risk, access to care, deprivation and social capital (for examples, see Leipert and Reutter (2005) and Cairns- Nagi and Bamba (2013)). However, there is a danger that- in perpetuating the idea of the possibility of resilience- we lose focus on people's suffering (Goward *et al.* 2010). Certainly, the disconnection between Mark's response to developing 'another' symptom and public health messages that promote 'individual responsibility' and 'resilience' is particularly apparent.

Such narratives of hopelessness can also be explored in relation to the concept of 'self- care'. As Dean (1989) explains, self- care can be understood as the multi- various behaviours performed to maintain or improve health. Although processes of self- care are complex and may including undertaking particular activities and not others, expected performances of 'self- care' were challenged by some participants in this research. For example, Michael actually explains that he has become 'destructive' in relation to the care of his health:

*Lindsay: "... do you think of the future and, if you do, what do you think about...?"*

*Michael: ...I have no, em, hopes or objectives as far as my life is concerned... I have no, I have no wishes for me and if somebody, eh, gave me a nice little cocktail one day to put me to sleep, I'd be perfectly happy with that. I'm not actively seeking, or have suicidal thoughts, but I'm getting a bit destructive in my own mind. And, em, I'm one of the few people who've started smoking again. Em, so what's the point? I mean, yeh it might give me cancer, but I'm going to die of something anyway so it doesn't really matter... the same applies to alcohol really- because alcohol isn't a very good fellow with the concoction of drugs that I take. But at the end of the day... I know it's being awfully selfish but if that were to cause liver failure or something- again, I've got to die of something.*

*Lindsay: mm*

*Michael: and I suppose it's my long suicide note. That 'I don't care'. And I know it sounds awful because if I became ill that would involve other people looking after me and, that, I acknowledge and just say 'sorry'."*

This 'lack' of self- care is an important aspect to the health narratives provided by some participants in this research. In the case of Michael, although I asked about the future in the broadest possible terms, his answer was framed solely in relation to his imagined health

future. Just as research with middle- class girls in independent schools showed that aspirations towards achieving a healthy body were linked to imaginations of improved social and physical capital (Rich and Evans 2013); so too is the inverse true in the case of Michael. This participant's 'lack' of belief in the desirability and achievability of improved mental and physical health seems to sit alongside a sense of hopelessness about every aspect of his imagined future.

A narrative of hopelessness is, thus, positioned as a significant feature of the imagined health futures of both Mark and Michael. The often hopeless health pasts, presents and futures described in this section certainly undermine dominant public health discourses that foreground ideas of 'resilience' and 'self- care'. Health trajectories often privilege ideas of 'improvement'; in the same way as broader imaginations of the future are based on notions of 'progress' (discussed in the previous section). But, as was demonstrated in this section, negotiating multiple illnesses and/ or disabilities is not just about trying to live with present bodily differences and difficulties; it is also about trying to cope with the imagination of hopeless health futures.

## 7.6 Relationships

In the final section of this chapter, I will explore how narratives of hopelessness are intertwined with and manifest in relation to other bodies. As has been demonstrated through my discussion in the previous two sections, the sense of hopelessness often felt by participants in this research undermines the idea that we are all looking towards happier futures. But participants in this research are still having to constantly (re) negotiate such imaginations of futures with other people who believe in and (re) produce dominant hopeful narratives. In this respect, imagining futures is a relational process in which people can find both points of commonality and difference in their imagined future life trajectories.

As an important aspect of the articulation of narratives of hopelessness, the interlinking of participants' imaginations of futures with other people's imaginations of futures forms a context in which multiply ill and/ or disabled bodies do not seem to 'fit in'. In the process of conducting this research, it became obvious to me that negotiating multiple illnesses and/ or disabilities is not only (often) accompanied by feelings of hopelessness about participants' future lives in an individual sense. Several participants expressed significant concern about how their future bodies would cope with changing relationships with other bodies. It is the imaginations of 'other' bodies' futures and the implications these futures will have on

participants' bodies that compounds the sense of hopelessness felt by many participants in this research. This point will be explored with reference to the experiences of Patrick and Angela who explain their worries about possible futures.

Firstly, the idea of 'letting people down' was a key theme in the narratives of futures presented by some participants in this research. Relationships with other bodies with different capacities, expectations and imagined futures were particularly difficult to negotiate in some instances. For example, Patrick explained this in relation to the thought of planning holidays and making decisions:

*"... if my wife says we should really book a holiday this year... the first thought is: 'I would like to, but how am I going to be then [at the time the holiday is booked for]?' I'm always unsure about the future... it's not just holidays, it's any decision. Big decisions. You think: 'I'd like to but I can't really commit myself fully to it because I don't know how I'm going to feel.' It sort of feels not fair on my partner, to my wife, do you know what I mean? Cause I can't really say I'm going to be brilliant when we go. So it definitely influences my decisions for the future. I don't feel confident in making decisions because of my conditions."*

From this extract it is evident that Patrick's imaginations of futures are tied to thoughts about the implications of his unpredictable health for making decisions with his wife. Managing such variability in his health is not only about thinking about his own future bodily states, but also about how these can relate to his wife's future bodily states. Although there may be many points of commonality with his partner's imagined future, in this instance Patrick presents his future body as at odds with being 'fair' to her. This is an interesting idea that underscores the importance of relationality in the articulation of narratives of hopelessness presented by participants in this research.

This issue of 'fairness' seems to be about endeavouring to mitigate the negative aspects of his health for the benefit of his wife. In weighing up this issue of fairness, Patrick has decided that is preferable not to book a holiday and not to make any big decisions than to face the prospect of having to let his wife down if his health status changes. Hence, an important part of negotiating multiple illnesses and/ or disabilities is about thinking about how particular present and future bodily experiences may relate to the expectations of other bodies. Of course, such expectations will vary according to the perceived role of particular people over the course of a person's life. For example, relationships between partners will often involve a different set of understandings and expectations than relationships between other family members. These relationship dynamics will also be shaped by particular singular and joint

histories, gender and age considerations as well as social norms.

Reflecting on this issue of 'fairness' in relation to imaginations of futures has been particularly challenging for me. Connecting narratives of hopelessness to narratives of fairness underscores a tension that some participants in this research constantly (re) negotiate. For Patrick, it was more important to be fair to his partner than to hope that it might be possible to go on a holiday (something that he and many others consider to be a desirable and pleasurable activity). Hence, narratives of happiness and hopefulness are often not considered to be as important when related to other narratives (such as 'fairness'). This perspective unsettles dominant conceptions framing how people 'should' think about the future.

But it is still difficult to consider that the possibility of 'letting people down' is more important than feeling hopeful about the future. When Patrick expressed his perspective on this issue during our interview I felt uneasy about the idea that 'letting people down' should take precedence when considering future plans. But this 'uneasiness', I have come to realise, is firstly a reflection of the dominance of narratives of hope that routinely prompt a rejection and devaluation of anything that threatens the (re) production of the narrative. Secondly, and in partial contradiction of this first point, Patrick's concern about 'letting people down' fits into a broader narrative on disability that positions people living with chronic illnesses and disabilities as an inconvenient problem. The obvious tension between these two ideas means that the relational negotiation of multiple illnesses and/ or disabilities is often a difficult process for participants in this research.

Within medicine, an emphasis on hope feeds into and feeds off dominant, broader societal narratives of happy and hopeful futures. For example, the development of new medical technologies are often thought of as providing hope for people living with particular forms of bodily difference (Lupton 2003). This is apparent if we consider people's experiences of infertility and the hope that medical advancements (such as IVF) can enable pregnancies. In relation to this particular technology, there is hope for some people experiencing difficulty in becoming pregnant. But, as Lupton (2003) explains, the side-effects of such treatment are often paid little attention. In this sense, the pessimistic aspects of particular diagnoses and treatments are downplayed because they undermine dominant narratives of the future as happy.

So when Patrick discusses the negative aspects of his multiple illnesses and/ or disabilities, this challenges the idea that things will get better in the future. My own

uneasiness at Patrick's lack of hope about the future is a reflection of the pervasiveness of a narrative of the future that emphasises the potential for happiness. When Patrick mentions the 'unfairness' his wife faces if a holiday booking needs to be cancelled or decisions need to be changed, it is evident that hope is both a singular and a joint narrative that is subject to disruption. It is also a narrative that needs to be considered in relation to other dominant narratives in society, such as the desire for fairness.

Thinking about Patrick's experience in further depth, his concern about letting his wife down is also part of a broader narrative that re (produces) the idea that illness and disability experiences are inconvenient to other people. In Patrick's case, narratives of his future are understood in relation to expectations about the degree to which his wife is treated fairly. The articulation of this concern is reflective of the prejudice (both blatant and subtle) that often make people with disabilities feel less valuable in our society (Deal 2007). These forms of prejudice are multi- various and can include the failure to be considered for workplace promotions or the creation of problematic social policies and services (Deal 2007). Within this context, Patrick's concern about being 'fair' to his wife should be understood as symptomatic of a society that devalues particular forms of human experience.

For example, in Patrick's case, the association between going on holiday and a sense of hopefulness is reflective of a hierarchising of particular experiences according to their perceived value. Following the work of Ahmed (2010), particular objects (such as going on holiday, in Patrick's case) are connected to happiness. Ahmed (2010) writes that:

"Things become good, or acquire their value as goods, insofar as they point toward happiness. Objects become 'happiness means'. Or we could say they become happiness pointers, as if to follow their point would be to find happiness. If objects provide a means for making us happy, then in directing ourselves toward this or that object, we are aiming somewhere else: toward a happiness that is presumed to follow." (Ahmed 2010: 26)

Patrick's account of the difficulty he faces in going on holiday can be understood as a difficulty in accessing his desired happiness object. In this sense, the experience of not going on holiday because of illness becomes a devalued experience. For Patrick, this devaluation is highly relational- given that his wife would possibly experience 'unfairness' if plans need to be changed. Hence, the theme of 'letting people down' was an important aspect of research participants' narrations of their futures. Through discussion of this idea, the relationality of narrations of futures comes into focus. Talk of 'unfairness' and the inability to achieve particular joint happiness goals underscores the ways in which narrations of

disability are lived out and intimately connected to 'other' bodies. Consequently, an important aspect of the hopelessness that several participants in this research feel about their futures is about how relationships might be strained as a result of their multiple illness and/ or disability experiences. Alongside discussion in the previous two sections, examination of the theme of 'letting people down' further underscores the extent to which people negotiating multiple illnesses and / or disabilities do not 'fit into' imaginations of the future as happy and hopeful.

Just as the idea of 'letting people down' was mentioned during several people's accounts of their present and future circumstances; so too was there considerable concern amongst participants about the thought of losing important people in their lives. The love and support that certain family members and friends provided was often crucial to participants' ability to live with their multiple illnesses and/ or disabilities. The thought of these people dying was very distressing to some participants, especially when participants' found it difficult to form and maintain relationships. It is this tying together of imagined futures with other bodies that meant narrations of future illness and disability expectations were often imbued with a sense of hopelessness.

This point is explored with reference to Angela's account of the support her mother currently provides and her concerns about how this might change in the future. She told me that:

*Angela: "my mum... supports me a lot. I couldn't manage without my mum.*

*Lindsay: and do you get any support from anybody else?*

*Angela: I don't have any friends [pauses]*

*Lindsay: oh right*

*Angela: I don't manage well with relationships.*

**LATER IN THE INTERVIEW**

*Lindsay: and do you think about the future much or do you tend to think towards each new day?*



*Angela: when I look towards the future I generally tend to get myself into trouble and tend to get very depressed and very suicidal because I don't really see any good things in the future. I dream sometimes and come up with ideas of things I'd like to do. But realistically what I'd like to do is maintain my health so that I'm not in hospital- at least cope with basic, day-to-day things. And the future is very scary as well because I know that one day my mum might not be there."*

For Angela, imagining her future is intimately tied to the future of another body: her mother. At that point during our interview, this participant's sense of hopelessness about the future is explained by her concern that she 'couldn't manage without her mum'. Existing social sciences literature points to the important role that many parents have in caring and supporting adult disabled sons and daughters (see Shearn and Todd 1997, for example). But this role is often difficult to negotiate, given dominant expectations about the nature of relationships between parents and adult sons and daughters. In Shearn and Todd's (1997) research, for instance, they note that some parents continue to assist with the personal hygiene of adult sons and daughters, despite the physical difficulty and emotional strain of doing so. But this care work is vital and, if lost, presents a significant challenge for people negotiating multiple illnesses and/ or disabilities<sup>7</sup>.

Angela also noted that she does not have any friends and finds it hard to build relationships. Consequently, an important aspect of the hopelessness she feels is not only about the fact that she perceives the important relationship with her mother as ending at some point; but also as a result of the lack of other current and future relationships in her life. In this instance, the narration of the future as hopeless is also about the *lack* of other bodies that Angela's future is tied to. This demonstrates that isolation from other bodies is a source of hopelessness for Angela. If Patrick's experience of hopelessness is partially tied to the

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<sup>7</sup> Here, Angela explains the death of her mother as having a significant impact on her life because she relies on her for support when coping with multiple illnesses and/ or disabilities. It is important to note that although Angela explains this loss in term of hopelessness about her own future in negotiating multiple illnesses and/ or disabilities, I would imagine that (although not specifically mentioned by Angela) that these implications need to be understood as many and various. For example, there will probably be a significant emotional strain on a person who has recently been bereaved. Hence, although I am discussing this issue in terms of the support that Angela's mother currently provides, this is unlikely to be the only impact that a family member's death will have on someone's life. In this sense, it is important not to be reductive about the impact this loss could have. Indeed, the support that Angela's mother currently provides needs to be understood in the context of the broader relationship between the two of them- including joint histories, feelings of love and care.

idea of 'letting people down'; Angela's experience of hopelessness is partially tied to the idea of not having anyone to support her. This idea of absence is an important aspect of the narrations of futures presented by some participants in this research. Hence, when considering the significance of relationality in the articulation of narratives of the future it is important to consider the various manifestations of this relationality, including the implications of feeling that you are 'letting people down' (in the case of Patrick) and that you will not have anyone to support you (in the case of Angela). Unpicking this issue of relationality therefore reveals the ways in which narratives of futures are understood as hopeless by many participants in this research. Indeed, it often seemed to me during this research that participants were caught in a double bind: trying to form and maintain relationships involved problems such as the feeling that you are constantly being 'unfair' to someone; but failing or not being able to cultivate such relationships could result in the prospect of isolation and lack of support (in the case of Angela).

An important dimension of negotiating multiple illnesses and/ or disabilities is therefore about living with the imagination that future relationships will be fraught with difficulty. This point is underscored by Angela's statement that when she thinks about the future she tends to "get [herself] into trouble". Instead of imagining the future as happy and hopeful she uses the language of being 'realistic' about her expectations by just trying to focus on the present. The development of this strategy is reflective of a sense of hopelessness about her future not only in relation to her own bodily experiences of multiple illnesses and/ or disabilities; but also about how her imaginations of futures will tie together with the futures of other bodies (such as her mother). Alongside discussion in the previous sections about the importance of money and health, relationships are therefore a significant dimension to the narratives of hopelessness presented by participants in this research.

Taking the work of this chapter as a whole, I have sought to emphasise that the narratives of hopelessness articulated by participants in this research are multi- various. It is important to understand that particular imaginations of participants' futures should not be straightforwardly understood as just being about one aspect of life. Indeed, it is important to reflect on the multiple dimensions to participants' sense of hopelessness. This multiplicity is particularly apparent from the piece of ethnographic fiction included at the beginning of the chapter. From this extract of Mark's diary, it is evident that his feelings of hopelessness are interlaced together in relation to several 'different' aspects of his life, including: money, health and relationships. Each of these areas of life seem hopeless to Mark and feed off of each other to mean that his future is not imagined as full of hope and happiness.

Some people may argue that this sense of hopelessness felt by participants in this research is actually 'just' a 'symptom' of their illnesses and/ or disabilities (given that every participant in this research identified as living with singular or multiple forms of anxiety, alongside other illnesses and/ or disabilities). However, this narrow, medicalised understanding of people's imaginations of their futures would be to negate, silence and diminish the experiences of participants in this research. Instead, it is important to listen to the voices of these participants rather than simply dismissing their imaginations of futures because they present a challenge to dominant narratives of futures as happy and hopeful. As this chapter has sought to demonstrate, it is important to question the ways and means that narratives of happiness and hopefulness are (re) produced and what the implications are of these processes for people negotiating multiple illnesses and/ or disabilities. Indeed, not 'fitting into' such imaginations of happy and hopeful futures often comes at a significant emotional and social price for participants in this research and is just one dimension to the many 'problems' encountered by people negotiating multiple illnesses and/ or disabilities, as is extrapolated in the next and final chapter of this thesis.

## Chapter 8: Problems

### 8.1 Being a problem

The experiences of people participating in this research may be thought of as 'problematic'. Certainly, these 'problems' are always intertwined with particular individual and collective negotiations of 'broader' economic, social and political issues that shape people's lives. But, critically, the varied *bodily experiences* of people negotiating multiple illnesses and/ or disabilities are also understood as central to any analysis of specific individual and structural issues. Consistent with the significant focus that the social sciences have placed on bodies in recent times (Shilling 2007), the conclusions outlined in this chapter are centred on the idea that experiences of living with multiple illnesses and/ or disabilities may be viewed from the perspective of embodying (or being) a problem.

At the beginning of this thesis, I set out the three interlinked aims of my work. Specifically, these were to explore: i) manifestations of multiple illness and/ or disability experiences in different contexts, ii) implications of negotiating incomprehensible bodily experiences and iii) challenges that multiply ill and disabled bodies present for society. In addressing these aims, this thesis has unpacked some of the ways in which the lives of research participants are shaped and constrained by the material, emotional, social and political dimensions of living with a multiply ill and/ or disabled body. A running theme throughout this discussion was the sense that negotiating multiple illnesses and/ or disabilities was often about not fitting in, not behaving in expected or acceptable ways and not feeling valued in various contexts. Thus, the experiences of participants in this research can be considered as problematic from a number of perspectives.

Following the work of Ahmed (2009), the notion that particular bodies are positioned as the embodiment of particular problems is a powerful one. Not only that, but in relation to the case of promoting diversity in organisations (Ahmed 2009), particular bodies may actually *become the problem* (for example, non- white bodies in an organisation may become 'reminders' to a white leadership about the 'problem' of diversity). This process of reminding is reliant upon a tacit acceptance that particular bodies are the 'natural occupants' of particular organisational spaces and roles (Puwar 2004). Any body that contravenes this dominant order may be viewed as 'out of place'; in contrast to the bodies of those 'natural occupants' of particular spaces and positions, which are not marked out (Puwar 2004). In a

recent article, this issue was explored in relation to the discipline of geography. Domosh (2015) quotes an anonymous geography academic's experience in the classroom:

“Because I am raced, some of my students assumed that I wanted them to read an interview about race. I doubt that if I were a white professor they would have made this mistake. This is because people of color bear the burden of race while whites in the United States are unencumbered by it. Race exists for many whites only when they are in the presence of nonwhites—that is, the raced.” (anonymous, quoted in Domosh (2015): online)

In this example, the professor is positioned by the students as the embodiment of the ‘issue’ of race. In that sense, bodies that ‘unexpectedly’ occupy such spaces and positions are reminders of the problems that have not yet fully been addressed.

This is important because, as has been demonstrated throughout this thesis, ‘being a problem’ has profound implications for the lives of people negotiating multiple illnesses and/ or disabilities. It is no coincidence that the feelings of anxiety, isolation and humiliation that prominently feature in participants’ accounts presented in this research are often expressed in tandem with specific examples of how their bodies are not performing in expected and accepted ways. For instance, in *Chapter 7* Patrick explains that he feels “... robbed of all [those] pleasures I could have had without OCD...”. The problems he faces in his life are, therefore, always positioned in relation to what he and others expected and expect from their lives. Given that his life has not been pleasurable in several respects, it thought of as ‘problematic’.

Fleshing out this idea further, it is important to highlight that ‘being a problem’ has implications for both individuals living with multiple illnesses and/ or disabilities and the people, groups and institutions responsible for responding to and accommodating such bodies (such as transport providers, educational institutions and employers). Indeed, we must always question who the bodies of people with multiple illnesses and/ or disabilities are a problem for and why they are viewed as problematic at particular times and spaces. It is categorically not the purpose of this chapter to argue that people participating in this research are ‘problems’. Rather, this chapter seeks to bring together discussion presented throughout this thesis to critique the positioning of people with multiple illnesses and/ or disabilities as ‘problematic’ by particular people, at particular times and spaces. Hence, the aim of this chapter may be expressed in the form of a two interlinked questions: In which ways are the bodies of people participating in this research imagined and understood by particular people as ‘problematic’ in specific contexts and for particular purposes? Secondly, what are the consequences of this positioning for the lives of people who become the problem?

Throughout this thesis I have sought to explore the many ways in which people negotiating multiple illnesses and/ or disabilities experience difficulties. This has been achieved through exploration of various spaces and contexts which participants negotiate on a daily basis, including treatment and mobility settings. But in this conclusion I want to bring together the discussion presented across these chapters to unpack how and why the experiences of participants may be thought of as problematic. There are three aspects to this argument.

Firstly, in the remainder of this section, I will explain that the lives of people negotiating multiple illnesses and/ or disabilities have had scant attention even from groups who may be expected to be interested in such experiences (such as social scientists and medics). Hence, participants in this research are positioned as *embodying a problem that has been neglected*. Secondly, people negotiating multiple illnesses and/ or disabilities are considered as *problematic because they destabilise and challenge many of society's dominant ideas and attitudes about bodies*, including ideas of 'clarity' and 'stability'. Thirdly, given that the occurrence of particular combinations of illnesses/ disabilities may be quite rare (as an example, there are not many people living with the particular combination of anxiety, depression, osteoarthritis, high blood pressure and ovarian cancer), *any one body may be thought of an isolated problem* that does not prompt much consideration. As I shall argue, there is a real failure to view the experiences of people with multiple illnesses and/ or disabilities as a collective. In presenting these conclusions, I will weave together ideas discussed *across* the preceding chapters- with the aim of linking together epistemological, methodological and empirical knowledges. As part of this effort, and unlike most other social sciences literature, this involves referring back to the data generated and presented throughout this thesis. Consistent with the feminist approach taken to this research that values different forms of knowledge, this writing approach will include presenting participant quotations (in an abridged format because of space constraints).

Beginning, with the idea that the experiences of people negotiating multiple illnesses and/ or disabilities are neglected, I would specifically like to set out the ways in which not enough attention has been placed on this issue. Significantly, as was demonstrated in *Chapter 4* in particular, complete understanding of other people's experiences can never be 'achieved' but this does not diminish the importance of hearing and responding to the voices of people negotiating multiple illnesses and/ or disabilities. Consistent with feminist epistemologies, being attentive to the voices of marginalised groups is a key feature of this research. For instance, just as the voices of women with disabilities have typically been overlooked (such as in relation to the privileging of personal assistance provision to enable access to workplaces, whilst playing little focus on the provision of assistance to help at home or with

childcare (Morris 1996, cited in Thomas 1999)); so too have the voices of people with multiple illnesses and/ or disabilities been curtailed or ignored.

Academia is one context in which this curtailment is clear. Consequently, the experiences of people with multiple illnesses and/ or disabilities are often not heard. In the social sciences, considerable attention has been placed on the experiences of people with particular illnesses and/ or disabilities (see Davidson and Henderson (2010)- autism, Dyck (1995)- multiple sclerosis and Smith (2012)- epilepsy), alongside a focus on particular aspects of living with illness and disability more generally (for example, in relation to the stigma associated with living with a disability (Lupton 1999) and the problems of accessibility to public spaces (Imrie 2012 and Lingsom 2012)).

Part of the reason why the experiences of people with multiple illnesses and/ or disabilities are not well understood is a consequence of the division between academics focusing on 'chronic illness' and those focusing on 'disability'. Specifically, I argued in *Chapter 2* that, particularly in the 1990s, those describing themselves as working within disability studies took an approach to research that was at odds with those working within the broader social sciences (especially in sociology). There are, of course, several reasons for this difference but the two I focused on were (i) research paradigm and (ii) theorisations of disability. Whilst disability studies writers typically worked within an emancipatory research paradigm (Barnes 2008); those in the broader social sciences tended to take a medicine- based approach (Finkelstein 1998). The emancipatory approach taken within disability studies placed the aim to empower people with disabilities at the centre of any research conducted within the discipline (Barnes 2003). At that time, this was a particularly important endeavour, given social science's problematic, highly medicalised approach to research (see *Chapter 2* for a discussion about why this medical approach was so problematic, explained in relation to Le Court Cheshire Home). But this emancipatory approach was also troublesome because of its neglect of bodies (such as those living with chronic pain) whose experiences cannot always be improved by making societal changes. This meant that whilst disability studies tended to often focus on people with (stable and visible) disabilities whose lives could be improved by making societal changes; the social sciences tended to focus on the bodies of people who were often described as 'ill' (typically with unstable and invisible conditions). Given this division, people living with both 'illnesses' and 'disabilities' posed a problem to academia. If bodies have already been divided up along these disciplinary lines; how could people who undermine this boundary possibly be heard within academia?

In addition to this difference in research paradigm, the dominance of the social model of disability in disability studies meant that the place of the body in academia was a source of

controversy. In line with the social model of disability, disability studies writers made a distinction between *impairment* and *disability*. The distinction rests on separating bodies from society- with an impairment defined as an aspect of an individual body and disability defined as occurring because an individual with an impairment is 'disabled' by society (Shakespeare and Watson 2001). As I demonstrated in *Chapter 2* of this thesis, whilst disability studies emphasised this distinction between bodies and society, the broader social sciences was problematizing this dichotomy. Indeed, in several of the social science disciplines, the body was the subject of much discussion (for example- Dorn and Laws (1994) (geography), Featherstone and Turner (1995) (sociology) and Lock (1993) (anthropology)). This difference in focus between disability studies and the broader social sciences meant that the disciplines were, epistemologically, far apart.

This discussion presented in *Chapter 2*, and summarised in this final chapter, frames the academic context that has given rise to a neglect of the voices of people negotiating multiple illnesses and/ or disabilities. It is important to emphasise that there are more than two reasons that explain the absence of these voices from academia, but an exploration of the issues of (i) research paradigm and (ii) theorisations of disability in this thesis begin to account for the divide between disability studies and the broader social sciences. This disciplinary divide relies upon a problematic slicing up of bodily experiences according to the categories of 'illness' or 'disability'. The first 'problem' presented in this conclusion, therefore, is that the experiences of people with multiple illnesses and/ or disabilities have been neglected by academics. Here I reiterate the point that 'full' understanding can never be achieved, but it is valuable to listen and respond to the voices of this group of people. By focusing on this topic, I feel that this thesis contributes towards addressing this problematic gap within academia.

As well as this neglect within academia, this research has demonstrated that the experiences of people with multiple illnesses and/ or disabilities are not heard (or responded to) within medicine. In *Chapter 5* of this thesis in particular, I explored some of the ways in which participants in this research negotiated feelings of rejection in treatment settings as a consequence of living with multiple illnesses and/ or disabilities. Building on the work of Johansson *et al.* (1996) about feelings of rejection experienced by people with unexplained musculoskeletal disorders, I set out some of the difficulties associated with accessing treatment and care when bodily experiences do not neatly 'fit into' pre- defined medical categories and settings. Specifically, I demonstrated that people with multiple illnesses and/ or disabilities constantly face having to negotiate issues of urgency and relevance within treatment settings in order to access appropriate services.



The experience of Stephanie after she was diagnosed with clinical depression and suicidal tendencies illustrates the detrimental effect that an ‘urgency’ to treat one illness had on the possibility of treating a second illness. She explains that:

*“I felt like the bulimia just got swept under the carpet like it didn’t matter, [but] in terms of what I actually did and what was affecting my life on the most frequent basis, it was definitely bulimia. But the one that they were worried about in terms of severity of consequences was depression and suicidal tendency[ies]...”*

The people responsible for Stephanie’s treatment went through a process of assessing which of her illnesses were the most ‘urgent’, meaning that her diagnosis of clinical depression and suicidal tendencies became the focus of interest. But the fact that Stephanie expresses her discontent with this decision underscores the different ways in which clinicians and patients sometimes feel about assessing the appropriateness of a particular clinical focus. This example, I argue, demonstrates one way in which medicine has a very limited understanding of the experiences of people with multiple illnesses and/ or disabilities. But listening to patients’ perspectives in relation to the negotiation of ‘urgency’ could open up alternative ways of understanding what is meant by this term (for example, Stephanie views her bulimia as a more ‘urgent’ clinical focus because it affects her more frequently than her clinical depression and suicidal tendencies do).

Secondly, the work of this thesis has shown that the issue of relevance is significant to the negotiation of multiple illnesses and/ or disabilities in treatment settings. Assessing the ‘relevance’ of any one bodily experience to the access of ‘relevant’ forms of treatment is something that can prove contentious. In *Chapter 5*, this point was explained by Vicky in relation to her trying to access an eating disorder clinic:

*“... I sometimes refer to myself as having OCD and I sometimes refer to myself as having an eating disorder.... their reason for turning me away from an eating disorder clinic was because I didn’t have a problem with weight or body image and that made me quite angry...”*

In this instance, ‘matching’ her complex and multiple diagnoses identities (given that she sometimes referred to herself as having OCD and sometimes as having an eating disorder) to a particular treatment setting was a source of disagreement between Vicky and her doctor. In the same way as Stephanie had difficulty in negotiating the focus of her doctor’s attention; so too did Vicky in accessing an appropriate service. Hence, medicine is argued in this thesis to have a fairly limited understanding of the lives of people with multiple illnesses and/ or disabilities.

I accept that there is a difference between 'understanding' particular experiences and 'accepting' and 'responding' to those experiences. It is perhaps the case, for example, that medics do feel that they understand people's experiences, but would say that they are acting in the best interests of the patient by assessing the relevance and urgency of particular illnesses/ disabilities over others. However, I think the experience of Stephanie showed that she was not even given the opportunity to voice her concerns (as her bulimia diagnosis was 'swept under the carpet'); whilst Vicky was simply dismissed (by being 'turned away' from her preferred treating setting). These processes of silencing the voices of people with multiple illnesses and/ or disabilities point to the unequal power dynamics at play between doctors and patients. Hence, as an important conclusion of this research, the power-laden negotiation of issues of 'urgency' and 'relevance' work in medicine (in some instances) as a barrier to the understanding of people's experiences of multiple illnesses and/ or disabilities.

As well as this limited understanding in medicine, this section has served to highlight some of the reasons why academia has not placed enough of a focus on the voices of people negotiating multiple illnesses and/ or disabilities. Together, a summarised discussion of these two important contexts has demonstrated the extent to which participants in this research embody a problem that is not well understood. Whilst this may seem like a fairly simple point, it is one of three major conclusions arising from this research. Significantly, the lack of attention on the experiences of people with multiple illnesses and/ or disabilities has had sometimes devastating effects on individuals. These effects have been discussed in some detail in this thesis, particularly in relation to the impact this lack of focus has had on access to medical treatment and public transport. Although I argue that the experiences of people with multiple illnesses and/ or disabilities can never be fully 'understood' (as is the case in relation to any other individual or group of people), there is a significant opportunity to listen and respond to the voices of this marginalised group. The importance of achieving this potential has been discussed in specific relation to academia and medicine in this concluding section, but it applies in many other contexts that are beyond the scope of discussion here (such as education, employment and care). People negotiating multiple illnesses and/ or disabilities certainly embody 'a problem' for such institutions; but one that needs to start being paid attention to.

## 8.2 Problematising dominant ideas about bodies

The second major conclusion offered in this thesis is that, not only are people with multiple illnesses and/ or disabilities neglected, but their experiences also pose a threat to the (re)

production of dominant attitudes about how bodies 'should' function in our society. Listening to voices of people with multiple illnesses and/ or disabilities, I argue, exposes the fragility of standardised ideas about the roles and capacities of bodies. This issue was frequently returned to throughout the research (in relation to many different topics) - reflecting its resonance in the lives of participants. Existing (especially feminist) health and disability literature points to the ways in which particular bodies undermine notions of the body as clear, consistent, rational and bounded. As shall be summarised in this section of the chapter, my research adds to this literature by demonstrating the (often) unique and complex ways in which the experiences of people living with multiple illnesses and/ or disabilities present a challenge to dominant conceptions about how bodies should work and relate to other bodies. Significantly, this thesis does not just work to 'confirm' this feminist critique of a problematic and pervasive view of bodies as clear, consistent, rational and bounded. It also explores new and different ways in which the lives of people with multiple illnesses and/ or disabilities are shaped by the propagation of dominant perceptions about how bodies 'should' operate and what, in turn, this tells us about our understandings of bodies.

Firstly, this research has sought to challenge the conception that bodies are (or at least, 'should be') stable over time. Within the feminist social sciences literature, the unpacking of problematic forms of dichotomous thinking helps us to move away from the practice of making easy and clear-cut distinctions about identities, bodies, ideas and spaces. Bondi (2004: 5) for instance, emphasises the importance of a "politics of ambivalence" in which the intricacies, ambiguities and contradictions of our lives are attended to. In doing so, specifically in relation to this work, key binaries that frame our understandings of bodies (such as (i) stable/ unstable, (ii) rational/ irrational and (iii) disabled/ able-bodied and (iv) ill/ well) become eroded. Paying attention to and moving towards this "politics of ambivalence" (Bondi 2004: 5) has enabled significant insights to be made into the complexities and ambiguities involved in participants' experiences of negotiating multiple illnesses and/ or disabilities. Specifically in relation to the issue of 'stability', this research not only contributes towards the feminist literature that challenges the perceived fixity of ill and disabled bodies, but it also sets out new ways in which this is manifest in the lives of participants.

Instability, as has been demonstrated, is a central feature of the lives of people interviewed over the course of this research. Attending to the unpredictability of multiply ill and disabled bodies underscores the significance of temporality to our understandings of health, illness and disability more broadly. In *Chapter 7*, this was evident from an exploration of the difficulties that Anna faces in undertaking work, whilst living with multiple health problems. Existing social science literature has framed some people's illness experiences in terms of 'good days' and 'bad days' (see Charmaz 1993), but my reading of Anna's experience

suggests that her experience of bodily variability is much more complex than this. She explained that:

*“... I may have a few good days where I can go in, I can get on with my work. But all of a sudden I kind of almost flip out...”*

As I argued in *Chapter 6*, the ‘sudden’ change in Anna’s body undermines the dominant and accepted temporal intervals at which bodies are expected to operate within. Notions of ‘the day’ or ‘the working week’ seem inconsistent, here, with the fluidity and uncertainty associated with negotiating multiple mental health problems. Recognising this unevenness in bodily capacities across a range of temporal intervals is something that Lightman *et al.* (2009) have challenged in relation to the idea of ‘good days’ and ‘bad days’. They argue that such a characterisation of bodily variability encourages dichotomous, simplistic thinking about people living with physical disabilities (Lightman *et al.* 2009). Following that line of thinking, this research (and, specifically, Anna’s experience) indicates the need for a much more nuanced approach to understandings of bodily variabilities over time. Negotiating multiple illnesses and/ or disabilities often means living with the ‘unexpected’ and ‘unpredictable’- something that it is important to take account of when seeking to explore the lives of the people who participated in this project.

The difficulties associated with living with such instability cannot be overstated. An important aspect of this thesis is the foregrounding of the emotional implications of negotiating such a multiplicity of unstable bodily experiences. At this point I would like to re-emphasise that negotiating any one illness and/ or disability can cause significant difficulties for individuals and it is important to recognise and respond to these issues. The work of this thesis should not be viewed as an attempt to hierarchize illness and disability experiences. For example, it would be hugely problematic to suggest that living with one illness/ disability is easier than living with two illnesses and/ or disabilities. My perspective, based on participants’ accounts, is that living with multiple illnesses and/ or disabilities may be understood from a layered perspective in which complex (unstable) emotions and identities are interwoven together.

It was in *Chapter 7* that some of the manifestations of these unique geographies were particularly evident. For instance, Mark’s experience of anxiety, chronic pain and irritable bowel syndrome (IBS) presented significant uncertainties about the possibility of travelling into the centre of his nearest town. The rigidity of the bus timetable, alongside a *variable* anxiety about a lack of toilet access (given his IBS) and the pain of sitting on a bus meant that the problems associated with negotiating multiple illnesses and/ or disabilities are layered together in quite uncertain ways. Mark’s capacity to attempt his desired mobility

(getting the bus into town) is changeable over time, relating to the interactions between his multiple bodily variabilities. He noted that:

*"[I can't guarantee] to be where I have to be at a certain time... I might be half way up the garden path and I've got to double- back to the toilet... [then my] bus [is] missed... you know? So the anxiety- it comes out with... your [chronic pain] and your bowels."*

This abridged excerpt not only indicates the uncertainty associated with the interaction of multiple illnesses and/ or disabilities, but the tone in which Mark spoke to me about this topic (which is perhaps only apparent from listening to the interview recording itself) is also reflective of the emotional implications of such a level of uncertainty. Living with multiple bodily variabilities also means living with (often) difficult emotions embedded in relational expectations about the 'typical' rhythms of daily life.

The negotiation of these relational expectations is bound up with the (re) production of particular identities. In the context of missing a bus, for example, the psycho- emotional aspects of disablism (Reeve 2002) may mean that this one instance of 'failure' may be understood within a broader identity politics in which the narration of failure becomes a common theme. Processes through which people with disabilities are made to feel as though they are failing to perform accepted and expected behaviours may have the consequence of embedding failure in particular identities at particular times and spaces. This link between a multiplicity of bodily variabilities, emotions and identities is important.

Highly changeable bodily experiences and capacities mean that 'failure' becomes an important aspect of the identities of many people who participated in this research. For example, specifically thinking about the methodological issues associated with conducting this project, several participants were very concerned about whether they were performing well enough during the interview process. In *Chapter 3*, this is particularly evident from Angela's repeated questioning of whether she is 'doing alright' during our interview. Despite reassurance, it was evident to me that a much more ingrained anxiety about 'failure' was on her mind. Demonstrably, negotiating multiple bodily variabilities has important implications for the (re) formations of particular identities at particular times and spaces. Undermining society's desire for predictability and stability has been shown in this thesis to come at a high price: working towards embracing and valuing a "politics of ambivalence" (Bondi 2004: 5) certainly seems like a distant prospect for many participants in this research.

A second 'problem' that people negotiating multiple illnesses and/ or disabilities present is in relation to the 'lack' of clarity that characterises many of their bodily experiences. It was Pinder (1996) who explained that our institutions work on the basis of having (or, at least, striving for) simplicity and clarity. In relation to work and productivity, for example, bodies are

required to be “either sick or fit” (Pinder 1996: 136) (original emphasis). But many people living with both singular and multiple illnesses and/ or disabilities do not ‘fit into’ such straight- forward categorisations of bodily capacities and experiences. This lack of clarity presents an inconvenient challenge to medicine and science- with disabled people embodying the limitations of these fields (Wendell 1996). The work of this thesis adds to this existing knowledge by, firstly, setting- out unique examples demonstrating that the issues of clarity are (often) embedded within the negotiation of multiple illnesses and/ or disabilities. Based on my analysis of these examples, this section of the concluding chapter, also underscores a second contribution to the existing literature: the extent and effects of this ‘lack of clarity’.

The drive towards clarity is a key feature of biomedicine (Crossley 2000). The dominance of this pursuit seems inescapable in our society, and is a topic that I struggled with during this research. In *Chapter 4*, I explained the way in which this problem is manifest in relation to my reading of Carolyn’s experience of being in hospital. She told me that:

*“... I was first in hospital with depression when I was 19 and I was in and out of the psych [psychiatry] unit for about seven and a half years and it was while I was in hospital that I developed the agoraphobia for some reason...”*

In theory, I accept that Carolyn did not know (of feel able to explain) the reason for the development of her agoraphobia, alongside depression. In practice, however, the pursuit of clarity is so engrained within me that it is difficult to change this learned thought process. But it is important to reflect on the ways in which the privileging of clarity can have important effects for people with multiple illnesses and/ or disabilities.

Indeed, this research has highlighted that the negotiation of ‘clarity’ takes place in the context of other (sometimes completing) narratives. Specifically, this research adds to existing work by considering the ways in which the pursuit of ‘clarity’ becomes highly relational. Many of the participants in this project may not easily ‘fit into’ a conception of bodies as ‘clear’ and ‘straight- forward’- but the extent of this ‘fitting in’ is always (re) produced unevenly over time and space. In *Chapter 4* this was particularly evident from Angela’s account of what she feels comfortable providing clarity about. After talking about various mental and physical disabilities that she lives with, towards the end of our interview she cautiously told me about ‘shameful’ bodily experiences that she may be compelled to talk about in the context of being assessed for disability benefits:

*“I feel ok talking about this but there’s other stuff that [pauses] I find shameful, but I shouldn’t...”*

Hence, Angela has to negotiate society's privileging of the pursuit of 'clarity' alongside trying to avoid telling other people about aspects of her life because of the ensuing shame she would feel. Being strategic about the disclosure of particular bodily experiences at particular times and spaces is commonplace amongst people living with illnesses (Charmaz 2002). But I think the experience of Anna highlights the bind that people negotiating multiple illnesses and/ or disabilities typically face: providing clarity may mean dealing with issues of shame (or other difficult emotions) but not providing clarity (if it is possible to provide it any particular instance) may mean that others question any one individual's credibility, with obvious implications for identity politics, feelings of belonging and access to resources.

As part of this strategic approach to the negotiation of clarity, some participants highlighted that- in the context of living with multiple illnesses and/ or disabilities- accessing support and resources is sometimes dependent upon the foregrounding of one aspect of bodily difference to the 'benefit' of another. For example, it was interesting that accommodations Carolyn required on public transport because of her mental health problems are now more 'available' to her because of the later development of back problems that require the use of a stick. She says that:

*"... with a stick it's like an outward sign that you've got some problems... it could be very difficult getting on a bus when I was fully able [when she was living with depression and agoraphobia- before the development of back problems]... I've always had to sit near the front [because of agoraphobia]..."*

Carolyn has always needed to sit near the front of the bus because of her agoraphobia, but this is a hidden disability that other passengers would not have been aware of. Later in life, when she began to use a stick to aid walking, she found it much easier to get a seat at the front of the bus. Hence, in this instance, Carolyn has strategically negotiated issues of clarity, to her benefit. Decisions about when it is advantageous to 'be clear about' a particular illness or disability experience (for example, when seeking access to support or resources) are also bound up with issues of visibility and stigma. In future research, I think it would be helpful to explore whether disclosure of more 'acceptable' visible and stable illnesses/ disabilities aids access to support and resources for more invisible and 'unacceptable' illnesses/ disabilities. The negotiation of issues of clarity, though, always takes place in particular contexts. One important contribution of this thesis is an exploration of the implications that negotiating issues of clarity has in different space and times, and in relation to particular bodies and identities.

For me, a particularly interesting aspect of this research was its consideration of the ways in which broader aspects of identity- such as age and gender- intersect with 'unclear' illness

identities to frame the 'value' of particular bodies and bodily experiences. Nettleton (2006) has written about the stress and upset associated with constantly having to explain bodily differences that do not 'fit into' any particular biomedical diagnosis. The pressure to be seen to be trying to explain such bodily differences, she notes, can be just as difficult to deal with as the symptoms themselves (Nettleton 2006). One unique contribution of this research was its (albeit limited) exploration of the relationships between multiply 'unclear' illness identities and other aspects of identities. For example, in *Chapter 4* I quoted Anna's experience as a young woman who did not know what was happening to her body whilst travelling on a bus:

*"I would get- like- really hot and sweaty and feeling sick and, you know, I'd just want to get off there. But at the time I didn't know why it was happening to me. I just thought it was me, sort of being a bit daft."*

I think it is important that Anna accounts for her experience in terms of her "being a bit daft". Her use of this term seems to indicate quite a dismissive attitude towards these difficult bodily experiences. This attitude is inseparable from broader gender and age identities that I argued (in *Chapter 4*) to be strongly linked to the routine devaluation of young women's experiences. A major limitation of this research is that further exploring these intersectionalities may inadvertently result in some participants' identities being revealed. Hence, there is significant scope for future work about the experiences of living with multiple illnesses and/ or disabilities to focus on how the negotiation of broader identity categories works in different contexts (if the researcher could be reasonably confident that the anonymity of participants could be maintained).

Hence, in several respects, the experiences of participants in this research present a challenge for a society in which clarity about bodies and bodily experiences is expected. The discussion in this part of the conclusion has sought to problematize the concept of clarity in relation to its particular manifestations in the lives of people with multiple illnesses and/ or disabilities. Alongside attending to the implications of participants' 'unstable' bodily experiences (for example, in relation to the profound emotional consequences of not 'fitting into' expected rhythms of daily life- discussed at the beginning of this section), the work of this thesis has sought to underscore the complex ways in which issues of 'clarity' are also important. The negotiation of a 'lack' of clarity about multiply ill and disabled bodies always unfolds unevenly across time and space. From the various contexts discussed in this short segment of the concluding thesis chapter, it is evident that negotiating issues of clarity is a key aspect of life for participants in this research.

In addition to undermining the idea that bodies 'should' be both 'stable' and 'clear' in all contexts, the final part of this section sets- out a third way in which people negotiating



multiple illnesses and/ or disabilities pose a problem to dominant conceptions of bodies. Particularly as a result of the 'instability' and 'lack of clarity' that prominently feature in participants accounts of their lives, difficult bodily symptoms may be considered as a 'problem' that cannot be 'solved'. The idea of 'problem solving' is an important pillar of biomedicine, but one which frequently fails to be realised by participants in this research. The lack of control associated with both living with and responding to the presence of multiple illnesses and/ or disabilities, is a challenge for those who would like to 'solve' the 'problems' that such bodies present.

It was in *Chapter 4* that the implications of biomedicine's desire to control and cure patients were explored in detail. Malterud (2000) has suggested that the bringing together of a patient's 'subjective' symptoms with a doctor's 'objective' conclusions is a key feature of biomedicine. But, as my work has demonstrated, sometimes symptoms cannot be easily expressed, understood, isolated, diagnosed and treated. Specifically, the experiences of people negotiating multiple illnesses and/ or disabilities present a problem that often cannot be solved by medics. This inability of biomedicine to 'solve' the problems experienced by participants in this research also feeds into (and feeds off) a broader context in which many aspects of these people's lives do not fit into expected and accepted norms. Thus, these difficult bodily experiences cannot be 'solved' in either a medical or non- medical sense.

The dominance of the idea of 'problem solving' is consistent with a narrative of the future that says we should all be working towards 'happiness' (Ahmed 2010). In the context of dominant narratives that privilege 'getting well' or 'becoming healthier', thinking 'negatively' about illness and disability experiences is unpopular- illness and disability are perceived as 'problems' that we should always positively work towards 'solving'. But because the multitude of (frequently) unclear and uncategorisable symptoms experienced by participants in this research cannot be 'solved', narratives of happiness and hopefulness are challenged. This is especially problematic when viewed in tandem with the rise of 'happiness industries' that re (produce) the idea that we all need to work towards 'progress' (Schoch 2006). Such pressure to 'be happy' means that 'solving' the 'problems' associated with living with multiple illnesses and/ or disabilities becomes a key pursuit. An important conclusion of this thesis, therefore, is that the bodies of people with multiple illnesses and/ or disabilities undermine dominant narratives of the present and future that privilege happiness. In turn, I suggest that these narratives result in the silencing of the (frequently pessimistic) voices of participants in this research. As will be summarised here (but was discussed in more detail in *Chapter 7*), this means that some dominant public health messages that are premised upon the pursuit and achievement of happiness and progress are called into question. In this section, this is discussed in specific relation to the concepts of 'health resilience' and 'self- care'.

Living with multiple illnesses and/ or disabilities sometimes means that addressing both existing and new bodily symptoms is not a priority. For example, Mark explained his response when he started passing blood:

*“... this is how depression and anxiety can make you think- I was passing blood... and I didn't care... I was so fed up, stressed, depressed... I just thought: 'if this is it; this is it'. I really, honestly, didn't care.”*

The development of 'yet another problem to add to the list' is not met with what many would expect as a response. It seems as though Mark's resilience to withstand and cope with difficult experiences is shaped by his broader experiences of bodily variability. Whilst it is important to relate issues of resilience to other identity categories (such as race, gender and class), Mark's experience also underscores the value of thinking about past and present bodily experiences when seeking to promote health resilience. The very idea of health resilience, however, has to be called into question here too. A notion of 'health resilience' relies on a hopeful imagination of the future; something which seems to have little resonance in the past and present lives of participants in this research. Following Grosz (2005) and Coleman (2008), an important conclusion of this thesis is its emphasis on the relevance of particular temporal modalities (pasts, presents and futures) in the (re) production of particular bodily experiences, capacities and responses amongst people negotiating multiple illnesses and/ or disabilities. Certainly, it is difficult to be resilient in the face of new bodily problems, given research participants' past and present bodily experiences.

Even 'managing' with the current range of bodily problems experienced by participants is extremely challenging. Being overwhelmed and unhappy about the past and present can mean that thoughts about 'the future' are too difficult to handle. The words of one participant stick in my mind because of his *certainty* that the future would be very painful, rather than considering any *possibility* that his life might improve. Michael's experience of negotiating multiple illnesses and/ or disabilities was definitively not a problem that could be 'solved'- he told me that:

*“... if somebody, eh, gave me a nice little cocktail one day to put me to sleep, I'd be perfectly happy with that. I'm not actively seeking, or have suicidal thoughts but I'm getting a bit destructive in my own mind. And, em, I'm one of the few people who've started smoking again. Em, so what's the point? I mean, yeh it might give me cancer, but I'm going to die of something anyway so it doesn't really matter.”*

Described as his 'long suicide note', Michael's perspective is the antithesis of public health messages that assume a level of 'self-care' (Dean 1989). Michael's words may be very difficult for some people to hear but it is important that such 'pessimistic narratives' (Ahmed

2010) are listened to. One reason (amongst many) that these words are so difficult to hear is because of society's dominant views about being positive and endeavouring to solve problems. A major conclusion of this research is the idea that many people negotiating multiple illnesses and/ or disabilities present a challenge to the notion that bodies can be controlled and that any troubling bodily experiences should be 'solved'. Furthermore, as is evident from this thesis, the voices of those bodies who cannot be 'cured' are frequently dismissed and devalued. Not fitting into narratives of 'progress' and 'problem solving' has (re) produced the isolation felt by people negotiating multiple illnesses and/ or disabilities.

This sense of isolation will be discussed in greater detail in the next section, but to conclude this section, I would like to re-iterate the second major finding of this research: participants in this research do not easily 'fit into' society's expected and accepted perceptions of the behaviours, experiences and capacities of bodies. Critically, this idea of 'not fitting into' cannot simply be explained in relation to the difficulties associated with living with one particular illness or disability. The often extensive and devastating effects of living with multiple illnesses and/ or disabilities undermine the key pillars that medics and others work towards- including the belief in the idea that we should pursue (and achieve) clarity and stability of bodily experiences. As has been demonstrated across this thesis, contravening this dominant set of biomedical ideas comes at a high price- not least because of the associated isolation that features strongly in participants' accounts of their lives.

### 8.3 Isolating the problem; the problem of isolation

Building on this, the final (and perhaps the most important) conclusion emerging from this research is closely linked to the 'problems' discussed in the previous two sections. The neglect of people with multiple illnesses and/ or disabilities in academia and biomedicine (amongst other fields), coupled with the 'challenge' their experiences pose to a dominant majority that relies on particular conceptions of bodies (as 'stable', 'clear' and 'solvable') has resulted in the isolation of this group of people. The manifestations and implications of this sense of isolation cannot be underestimated.

Feminist literature encourages attention to be placed on 'secrets and silences' in the research process, rather than just focusing on 'what is said' (Ryan- Flood and Gill 2013). These silences relate to specific instances (such as at one point during the interview I conducted with Angela- discussed in the previous section), as well as broader epistemological, methodological and empirical insights. One deafening silence evident from this research is the 'lack' of a sense of belonging that participants felt towards a broader

group/ category/ collective identified as negotiating multiple illnesses and/ or disabilities. Although participants narrated their illness and/ or disability identities in different ways, there was a tendency to refer to broad illness and disability categories and/ or to specific conditions. Accounts related to the former might include statements such as 'I have had mental health problems for many years' or 'being ill is not easy'. The latter might include statements such as 'I've got anxiety, but that is related to my IBS' and 'I know other people with schizophrenia as well'. These narrations tell us something about the sense of belonging that individuals feel towards particular collective identities.

During this research nobody seemed to narrate their experiences specifically in terms of belonging to a group of people living with multiple illnesses and/ or disabilities. Even in instances where participants did voice their multiple (sometimes contested) diagnoses at any *one point* during the interview, it was presented as a unique, complex, peculiar (and sometimes awkward, upsetting or 'humorous') *individual* case. For example, after Heather explained the many and various difficulties she faces as a result of living with multiple illnesses and/ or disabilities, she asked if I am going: "... to certify us [me] now, Lindsay?" This tongue- in- cheek humour worked in that context because it expressed Heather's awareness that most people would view the multi- various aspects of her bodily differences as unusual, weird and problematic.

Importantly, not only were participants silent about any sense of belonging to a broader group of people living with multiple illnesses and/ or disabilities, but some were also cautious about discussing several illnesses and/ or disabilities at any one point in time. Discussing 'too many' illnesses and/ or disabilities was risky for participants because their credibility may be called into question. This anxiety was evident when I asked Stephanie (detailed in *Chapter 4*) about how she imagined the future, with specific relation to her OCD and depression experiences. Before I could add more illnesses and/ or disabilities (that she had disclosed to me earlier in the interview) to this 'list', she interrupted me and wryly added the term "and all of the others" instead of listening to me going through each illness/ disability previously mentioned. Making the decision about when it is appropriate to 'list' a multitude of illnesses and/ or disabilities seems to be fraught with difficulty; involving a careful weighing up of how other people might respond in various contexts.

This is also a methodologically important point to bear in mind when conducting research with people negotiating multiple illnesses and/ or disabilities. Disclosing multiple illnesses and/ or disabilities may not only undermine the 'credibility' of people in some instances, but it may also be emotionally difficult for people (both for those living with and without multiple illnesses and/ or disabilities] to voice 'so many problems'. This was an issue that I noted

whilst conducting an interview with Carolyn, when I began to form a question about how she negotiates singular and multiple symptoms. Linking back to what this participant had previously told me, I listed some of her diagnoses but then thought against listing more of her diagnoses. That part of the transcript proceeds as follows:

“... so you mentioned having depression, anxiety and agoraphobia [when providing this list of diagnoses, I remember wanting to also mention her back problem. However, Carolyn seemed to have quite a sad look on her face at that point in the interview, so I thought that providing an ‘accurate’ list of all her illnesses and/ or disabilities might be difficult to hear.]”

My hesitation about voicing ‘too many’ illnesses and/ or disabilities stems from my concern about Carolyn’s wellbeing. On reflection, whilst it may be appropriate in some instances, ‘listing’ so many illnesses and/ or disabilities might be understood as reductive and upsetting. In future research, I think the ethics of ‘listing’ bodily variabilities could be explored in greater depth, perhaps specifically related to issues of stigma and belonging. The experiences of Heather, Stephanie and Carolyn (discussed in this section) all indicate the sense of isolation that strongly features in participants’ accounts of their lives. Voicing the presence of multiple illnesses and/ or disabilities is tricky in some instances- presenting difficulties related to issues of credibility, shame and sadness. Even when these difficulties are ‘overcome’, participants seemed to present their multiplicity of bodily differences as (peculiar, ‘humorous’ or awkward) *individual cases*. The absence of a sense of belonging felt amongst people negotiating multiple illnesses and/ or disabilities is a problem because of the deep sense of isolation associated with being *the only person* with such a multiply ill and disabled body, *the only person* who has got a range of awkward and contradicting problems and *the only person* whose problems are so ‘weird’ and ‘peculiar’ that they cannot be ‘solved’.

It is important to address this issue for several reasons. Although I accept that some people may not want to identify as belonging to any particular ‘group’, for others feeling part of a collective of people living with multiple illnesses and/ or disabilities may help to: (i) foster a sense of solidarity, (ii) reduce stigma and (iii) work towards societal change. The remainder of this section will explore each of these topics in turn, demonstrating the advantages of paying attention to the experiences of people with multiple illnesses and/ or disabilities (whilst acknowledging that my perspective is always partial and incomplete).

The first of these is the idea that feeling part of a collective could help to build a sense of solidarity amongst people living with multiple illnesses and/ or disabilities. Of course, one person’s experience may have features that are very particular to that individual, but this research has identified some broad themes resonating in the lives of many participants.

Each of the four empirical chapters presented in this thesis has explored a specific way in which people negotiating multiple illnesses and/ or disabilities do not always easily 'fit into' particular places, narratives and contexts. For example, many participants expressed the difficulties they had in negotiating issues of relevance and urgency in treatment settings, given their multiplicity of bodily 'differences'. The realisation that any one individual is not alone in experiencing these issues may have significant emotional benefits.

This sense of solidarity is a key feature of disabled people's movements- of which disability studies is an important part. The emotional advantages of coming together as a collective have been profound for some people who felt/ feel part of that movement. For example, in *Chapter 2* a quotation from Crow (1996) underscores the benefits that one particular theory (the social model of disability) developed as part of the disabled people's movement has had on her life (the quotation is shortened here but presented in full in *Chapter 2*):

"For years now this social model of disability has enabled me to confront, survive and even surmount countless situations of exclusion and discrimination... it has played a central role in promoting disabled people's self- worth, collective identity and political organisation. I don't think it is an exaggeration to say that the social model has saved lives." (Crow 1996: 207).

Regardless of people's different points of view about the academic merit of the social model of disability, it has been important in achieving a sense of collective disabled identity (although it is important to highlight that such identities are fluid, relational and context-specific). Bringing people living with multiple illnesses and/ or disabilities together more (either within or outside of the existing structures- such as the disabled people's movements and mental health awareness campaigns) could help to promote a collective identity amongst individuals who are currently isolated in many settings and contexts. This is certainly a difficult pursuit, but one which people already associated with existing health and disability campaigns, groups and activities are well placed to take forward. For example, it could be possible to build on the activities of organisations such as The Mental Health Foundation (2015) who are focusing attention on the links between physical health and mental health.

A second benefit of encouraging a sense of belonging amongst people negotiating multiple illnesses and/ or disabilities is the opportunity to reduce stigma. At many stages during this research, people made comments that highlighted the difficulties associated with discussing their multiply ill and disabled bodies. In *Chapter 4* this was evident from my discussion with Michael about whether he views his experience of mental illness as disabling:

“... you sit round a table with people who have the disability and I’ll talk about it perfectly happily about it as a disability. But when it’s in front of people who are not disabled you tend to hold back unless you’re being asked questions [laughs and points to me] because it is – it’s the embarrassment sometimes. Em and guilt- again... keeps coming back...”

Michael’s feelings of embarrassment and guilt about discussing his multiple mental health problems point to the significant stigma associated with doing so. Obviously, attempting to reduce stigma is a long and exhaustive process that calls existing ways of thinking into question. For example, challenging the relational (re) production of pity (as an important stigmatising emotion) is difficult because it would undermine existing (albeit problematic) social hierarchies (Hughes 2012). As Hughes (2012) explains, when any ‘benevolent’ individual or group expresses pity; the receiver is positioned as a subordinate. Challenging such forms of stigma is therefore not easy because it would mean undermining the relational (re) production of particular dominant and privileged bodies. Additionally, changing people’s attitudes has to be coupled with a change in the structures and institutions that (directly and indirectly) stigmatise the disclosure of multiple illnesses and/ or disabilities. Whilst not easy, it is of crucial importance to address this issue of stigma.

Strongly related to issues of fostering solidarity and reducing stigma, promoting a sense of collective identity amongst people living with multiple illnesses and/ or disabilities could help to enable societal change. Again, looking towards the disabled people’s movement, bringing people together to campaign for change has been effective in some respects (but there still remains a lot of work to be done). In much the same way as discrimination on the grounds of race or gender have been challenged in the U.K.; so too has discrimination on the basis disability become unacceptable (Shakespeare and Watson 2001) (particularly in work places and in public spaces). However, as this thesis has demonstrated, there is a significant need to go on tackling issues of discrimination and stigma across many settings and contexts. For example, as was highlighted in *Chapter 7*, it is concerning to note that the provision of ‘reasonable’ adjustments to enable access to the workplace is under threat in the U.K. (Harwood 2014). Continuing work to raise awareness of and address such issues is important in encouraging societal change.

But such ‘change’ should not become homogenised, idealised or hailed as the ‘solution’ to all of the ‘problems’ facing people negotiating multiple illnesses and/ or disabilities. It is easy to call for change, but different changes will be important to different people at different times and spaces. Indeed, as has been explored in this thesis, some people living with multiple illnesses and/ or disabilities may actually view particular forms of change as the problem. The temptation to take a rose- tinted view about the possibilities of transforming the lives of

participants in this research needs to be resisted. However, I do think that this research has highlighted several possible 'practical' changes that should be considered in relation to improving the experiences of people negotiating multiple illnesses and/ or disabilities. At this stage I would like to reference two tangible examples, whilst acknowledging that the way to achieve any of these changes is to, firstly, raise awareness of the issues associated with negotiating multiple illnesses and/ or disabilities in various contexts. Individuals, communities and institutions will have a particular grasp of what changes are important to them and how these can be best implemented.

Firstly, several participants in this research were not listened to by professionals when trying to discuss their symptoms and potential treatment options. Negotiating multiple illnesses and/ or disabilities is not easy; but it is sometimes made worse when clinicians impose particular explanations and treatments on patients instead of collaboratively thinking through the best possible ways forward. I appreciate this is very difficult because of the time constraints that doctors and nurses work under, but it is important to listen and respond to broader bodily 'problems' that cannot be isolated from one another within the body. There is a long way to go on this. Whilst conducting this research someone even told me that general practitioners actively discourage patients from discussing 'too many problems' during any one appointment because the doctors cannot handle thinking through several issues at once. Apparently, there was a notice displayed in her doctor's surgery advising patients of this request. It is instances such as these that need to be addressed.

Secondly, the mobilities of some people living with both singular and multiple illnesses and/ or disabilities would be improved if transport providers questioned the assumptions made about the particular capacities of bodies. In *Chapter 7* I argued that distances are imagined and experienced through a lens that privileged particular ideas about bodies. For example, whilst toilets may be provided on buses travelling 'long' distances, they are not provided on 'short' distance routes. The problem is that these perceptions of time and distance are premised on the idea that bodies uniformly behave in expected ways. As this thesis has demonstrated, conditions such as IBS and anxiety (discussed in relation to Mark's experience- see *Chapter 7*) mean that toilet access is not currently sufficient for some people. Considering the differences between bodies and in relation to the interaction of particular conditions (such as IBS and anxiety) is important in improving transport infrastructure and facilities.

These two practical examples of changes that could be made to improve the lives of people negotiating multiple illnesses and/ or disabilities underscore a key benefit of encouraging a sense of collective identity amongst this group of people. However, it is



important to note that these proposed changes (if desired by individuals and groups) may only take place following increased awareness about the unique difficulties, ambiguities and contradictions associated with living with multiple illnesses and/ or disabilities.

In this section I have demonstrated some of the key benefits associated with considering a more collective approach to increasing awareness and campaigning for change in the lives of people negotiating multiple illnesses and/ or disabilities. These changes, even if made, will not 'solve' all of the problems that participants in this research face but will help to address the sense of isolation that many participants feel about living with unique combinations of confusing illnesses and/ or disabilities.

Furthermore, considering a collective approach to the campaign for change will also feed off and feed into a more conceptual discussion of mental health and the body: a subject that would be relevant both within and beyond academia. Indeed, an important part of reducing stigma and fostering solidarity is in the questioning of how we currently think about mental health and bodies. As this research has demonstrated, it is important to destabilise tendencies to isolate symptoms within the body- a key pillar of biomedicine. What else is going on in the body and how bodies relate to one another is a key consideration in everyone's lives- including (but not limited to) people negotiating multiple illnesses and/ or disabilities. This means, for example, any one person's mental health is situated not only in relation to issues like age, gender and class- but also in relation to issues that are less typically thought about (such as the negotiation of additional illness and/ or disability identities).

The development of this conceptual work on relationality can also help us to think about how particular emotions seem to become associated with particular bodies- and what the implications of this are. In Chapter 7, for instance, I explored the ways in which feelings of hopelessness featured prominently in research participants' accounts of their lives. These feelings of hopelessness are at odds with dominant ideas about how bodies 'should' think about future trajectories. In this sense, it is important to consider the inequities and inconsistencies *between* bodies. As has been shown in this research, participants often pay a high price for contravening dominant societal ideas about the expression of particular 'negative' emotions, at particular times and in particular spaces. A focus on relationality is, thus, an important conceptual discussion that can be developed within research on mental health and the body- a topic that this research begins to contribute to.

## 8.4 Closing remarks: ways forward

At some points during this research, even thinking about 'ways forward' seemed like a hopeless exercise- given the complex, unclear and sometimes intractable problems associated with negotiating multiple illnesses and/ or disabilities. But I think this project provides an important starting point from which to address questions about individual, group and institutional awareness and responses to the experiences of participants in this research (and others with similar experiences). Importantly, I have sought to demonstrate that such experiences are neither peculiar 'individual' cases (though it is important to pay attention to the individual and individualising dimensions of these experiences); nor merely the summation of several singular illnesses and/ or disabilities. The idea that particular illnesses and/ or disabilities can be isolated within a body is clearly unsustainable. Instead, it is important to conduct further work to explore the ways in which such complex bodily experiences are relationally manifest amongst different people in various settings and contexts.

Firstly, I think there is scope to conduct research on this topic in different locations, both within the U.K and across the world. It was outwith the parameters of this project to undertake such work, but I think valuable insights could be generated about experiences of living with multiple illnesses and/ or disabilities in various political, social, economic and cultural contexts. For instance, the dominance of biomedicine in the U.K. forms a key part of the discussion presented in this thesis, but in other parts of the world where other modes of thinking are more dominant, people's experiences may be very different. Paying attention to these perspectives may yield insights about the ways in which multiply ill and/ or disabled bodies are theorised, understood, accepted and responded to amongst different groups of people.

This potential to conduct research in different locations extends to work on different spaces in which negotiations of multiple illnesses and/ or disabilities are lived out. In this thesis I have focused on clinical settings and spaces of mobilities (to name just two), but there is also scope to think beyond these contexts. For example, it would be interesting to conduct future work within community mental health settings (such as The Waddington Street Centre). Using methods such as participant observation and ethnography could generate insights about the spaces of mental health and how people negotiate their multiple illnesses and or/ disabilities in such a setting. Additionally, it would be beneficial to consider how such organisations respond to and accommodate people with multiple illnesses and/ or disabilities- when their primary focus is usually on a particular aspect of bodily difference (such as mental ill health in the case of the Waddington Street Centre).

Consistent with the feminist approach taken to conducting this research, I also feel that there is a huge opportunity to consider the processes through which particular individual and collective relational identities are (re) produced. As I explained in *Chapter 3*, ethical concerns meant that I have not been able to reveal more about the identities of participants in this research (such as in relation to race, class, age and to particular illness and disability identities). This is a major limitation of this research but future work could seek to flesh out some of these ideas. Taking more of an intersectional approach would yield important insights about who exactly is facing particular types of problems. For example, it could be interesting to explore how older people experience multiple illnesses and/ or disabilities- given society's expectation that growing older means living with various bodily problems. Within this context, are particular bodily experiences understood in relation to age identities or illness identities, or both?

Additionally, I am aware that this research took various forms of anxieties as a basis on which to recruit participants. In the end, people disclosed a broad range of physical and mental health problems to me- but different recruitment strategies may yield very different data. For instance, one way forward might be to not only concentrate on the experiences of people living with multiple illnesses and/ or disabilities. It could prove fruitful to think about the relationships between different bodies and their implications for our understanding about living with multiple illnesses and/ or disabilities. This work could extend to listening to the perspectives of carers, clinicians and public transport providers.

Lastly, there is scope to consider alternative ways in which data is both generated and presented about this topic. Whilst I think that conducting interviews worked well in this project, other people may feel more comfortable using different methods- such as focus groups or online methodologies. Presenting research about this issue in various formats is also important in raising awareness of the issues facing people negotiating multiple illnesses and/ or disabilities. For example, the ethnographic fiction written at the beginning of the four empirical chapters in this thesis will be provided to service users and staff at The Waddington Street Centre in the hope of communicating ideas from this research to a broad audience.

Hence, there are several possible 'ways forward' from this research. This thesis is offered as part of an effort to challenge the various ideas and attitudes that have resulted in the frequent isolation of people negotiating multiple illnesses and/ or disabilities. Although this thesis has demonstrated the difficulty in seeking to 'understand' the experiences of this group of people; it has also emphasised the significant problems associated with routinely

dismissing and devaluing these bodies because of their lack of clarity, comprehensibility and rationality.

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## APPENDIX A: Advertisement for research participants

# Do You Sometimes Feel Anxious?

If so, I would really like to talk with you  
about your experiences.



I'm a student at Durham University conducting research about people's daily life experiences of anxiety. This might include general anxiety disorders, panic disorders, OCD, agoraphobia, PTSD and others.

Please come along to the Art room on **Friday the 5th of April** at **12pm** to find out more about the project. Ali Lee will be there and lunch will be provided.

You can also e-mail me (**Lindsay Coyle**) for more information on:  
**[l.a.coyle@durham.ac.uk](mailto:l.a.coyle@durham.ac.uk)** or speak to me on Thursday mornings  
(when I volunteer in the café).



## APPENDIX B: Information for research participants



**Durham**  
University

*Shaped by the past, creating the future*

Department of Geography

### **Understanding People's Experiences of Anxiety in North- East England**

My name is Lindsay Coyle and I am doing a degree in geography at Durham University. I am interested in people's experiences of anxiety in the North- East of England. I would like to find out how having anxiety shapes daily life. This includes what places (e.g. home, shopping centres, parks etc) people like/ dislike to be in and why.

I would like to hear from people with anxiety who would be interested in being interviewed about their experiences. This could be anyone aged over 18 and living anywhere in the North- East of England. The interview should take around 1 hour and will be quite an informal conversation. If you agree, I would like to tape record the interview so I can type out what was said during the interview and then use it in the project.

Before beginning the interview there will be the opportunity to discuss the project with me and ask any questions. I will not begin the interview or use the tape recorder until you have given signed consent. You can withdraw from the study at any time without giving a reason. If you would like, I will keep what you tell me confidential (as far as is possible) and anonymise the data. It won't be possible to ensure complete confidentiality because somebody may guess who you are when I publish an article, for example. I will also use the name of the Waddington Street Centre in any published articles.

After the interview is over, I will type out what was said during the conversation. I will then use this information to produce articles to be published in academic journals and to write my final PhD. I will also give you a short summary of the study's findings.

If you would like to take part in this research or have any questions, please contact me using the details below:

E-mail: [l.a.coyle@durham.ac.uk](mailto:l.a.coyle@durham.ac.uk)



## APPENDIX C: Participant consent form

Durham University Geography Research

PARTICIPANT/ VOLUNTEER CONSENT FORM

**Understanding People’s Experiences of Anxiety in North- East England: Staff/ Volunteer Perspectives**

<p><b>Researcher’s Name</b> Lindsay- Ann Coyle</p> <p><b>e-mail:</b> <a href="mailto:l.a.coyle@durham.ac.uk">l.a.coyle@durham.ac.uk</a>  <b>telephone:</b> 0191 3341872  <b>address:</b> Durham University                  Department of Geography                  Science Laboratories                  South Road, Durham                  DH1 3LE, UK</p>	<p><b>Supervisor’s name</b> Prof Sarah Atkinson</p> <p><b>e-mail:</b> <a href="mailto:s.j.atkinson@durham.ac.uk">s.j.atkinson@durham.ac.uk</a>  <b>telephone:</b> 0191 3341871  <b>address:</b> Durham University                  Department of Geography                  Science Laboratories                  South Road, Durham                  DH1 3LE, UK</p>
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**Consent**

The purpose of this form is to ensure that you are willing to take part in this study and to let you understand what it entails. You will also get to keep a copy of this consent form.

- 1) Have you read and understood the participant/ volunteer information sheet? Yes/ no (please circle)
- 2) Have you had the opportunity to ask questions and discuss the study? Yes/ no
- 3) Have you received satisfactory answers to your questions? Yes/ no
- 4) Do you understand that you are free to withdraw from the study at any time and without having to give a reason for withdrawing? Yes/ no
- 5) Do you want to have your interview recorded using a digital audio recorder? Yes/ no/ not applicable
- 6) If you are providing written information (through e-mail or in a diary), do you agree for this information to be used in the study? Yes/ no/ not applicable
- 7) Do you want the information you provide to be treated confidentially, as far as is possible? (this cannot be definitively guaranteed) Yes/ no
- 8) Do you understand that the name of the centre (The Waddington Street Centre) will be used in any research outputs? Yes/ no
- 9) Do you agree to take part in this study? Yes/ no

Name (in block capitals) \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

## APPENDIX D: Interview schedule

People's Experiences of Anxiety- Question Schedule (semi- structured)

### **Introduction**

I'm a geography student and am interested in a typical 'day in the life of' yourself in order to work out the places where you do and why you go there/ how you feel when you are there

What are the places you go to?

Are there particular times you go to those places?

### **Feelings in Place**

What would you say are the places that you feel happiest in? (e.g. home, seaside)

What would you say are the places that you feel least happy in? (e.g. hospital, supermarket)

### **Getting around**

How do you get around? Why do you use that method?

Do you live in a city/ by the sea/ in the countryside?

How do you feel when in buses/ driving/ on trains?

Do you travel with anyone? Is this important?

### **Home**

How do you feel about your home?

Are there some rooms you use more than others?

What are the good and bad points about being

### **Work**

Do you work at the moment (including paid work, voluntary work, house keeping)?

How do you think work fits in with having anxiety?

### **Illness**

How long have you had anxiety?

Do you have any other conditions as well as anxiety?

How does anxiety affect your life?

Do you see there as being a difference in your life before you had anxiety and now?

### **Disability**

I'm just wondering how you would define disability and if you consider yourself to have a disability?

Do you think of yourself as chronically ill? What does the term 'chronically ill' mean?

What do you think the difference is in seeing yourself as having a chronic illness or as having a disability?

Do you think other things interact with having anxiety? E.g. gender, money

### **Other people**

How do you think other people see your experience of having anxiety?

Do you think they see anxiety as a chronic illness/ disability?

What about the media or government?

### **Future**

Do you see your experience of anxiety as changing in the future? How do you feel about that?

