

Living with Chronic Pancreatitis

A Hermeneutic Inquiry

**A thesis presented to the University of Dublin for the degree of
Doctor in Philosophy.**

by

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2009

DECLARATION

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SUMMARY

Title: Living with chronic pancreatitis: a hermeneutic inquiry.

Background: The stimulus for this study was borne of the researcher's clinical experiences of caring for those with pancreatic and biliary disorders. Significant encounters with patients with a diagnosis of chronic pancreatitis led to the conception that little was known about how people with the condition, and their families, live and manage. Recent international literature acknowledges the impact of this progressive and debilitating disease on psychological and social well-being and efforts have been directed at assessing health-related quality of life. However, in Ireland no comparable work could be located and it was proposed that the plight of those with a diagnosis of chronic pancreatitis remains unknown and hidden.

Aims and objectives: The overall aim of this interpretive inquiry was to develop an understanding and construct a meaning of living with chronic pancreatitis. In so doing, the everyday contextualised and culturally situated lives of individuals and their families who are living with the condition would be illuminated. It was proposed that through this exposition, a new understanding would be constructed that might have implications for healthcare professionals and the practice of caring for those who live with chronic pancreatitis.

Methodology: Philosophical hermeneutics after Gadamer was used to guide and direct the study the focus of which was in keeping with the aim of hermeneutics, which is to search for meaning in everyday human experiences and bring to the fore what is normally hidden. A purposeful sample was drawn from a population who were in the care of one hospital consultant and who had been diagnosed, and were living, with chronic pancreatitis. Family members who were willing to be included were identified by the primary participants. Fourteen primary participants and five family members were recruited to the study. Multiple, unstructured, formal interviews were the primary source of data and analysed using a hermeneutic analytical framework.

Findings: In this study, the meaning of living with chronic pancreatitis is 'enduring disruption. 'Enduring' as it is represented has a two-fold meaning. Primary it is an adjective to describe the perpetual and permanent nature of the disruption and occurs at physiological, social and psychological levels that constitute its three unifying categories. Enduring physiological disruption manifests itself in the form of unpredictable daily disruptions interspersed with episodes of escalating or salient physiological disruption. Enduring social disruption encompasses the perceptions of voluntary or enforced alterations to social roles, obligations and functioning. Enduring psychological disruption is embedded in the participants' discernment of an altered self in illness and a sense of being different to the person they were before being diagnosed with chronic pancreatitis. This is signified as disturbance in their cognitive and affective sense of normal, delineated as 'disturbed normal'.

The interrelationship between the unifying categories was determined to represent the 'what' of 'suffering'. Three forms of suffering; suffering caused by illness and treatment, suffering caused by care and suffering that relates to existence were evident. The physiological assault associated with unpredictable daily disruptions and the attendant treatment regimes represents suffering related to illness and treatment. At times, this suffering is amplified by that which can arise in the context of healthcare and through relationships with healthcare professionals and symbolises suffering related to care. In addition, vulnerability and uncertainty that materialise as a consequence of tangible physical and social losses contribute to psychological distress and generate suffering related to existence. Because of the unpredictable nature of chronic pancreatitis, suffering is endless and likely to never be fully alleviated.

Enduring, as a verb, also means 'to cope with' and/or 'to tolerate' and is about how the participants and their families 'come to know' and 'adjust/manage' through the development of their self-management strategies within an overall transition from 'well' person to a person with chronic pancreatitis. Transition to being a person with chronic pancreatitis is a process of assimilation and acceptance of a life permanently altered and a realisation that a return to their 'old' normal is no longer possible. Nonetheless, coming to terms with their illness is a struggle emotionally. While they slowly become more proficient in their self-management, most participants have not yet identified an alternative life construction that is acceptable to them.

Together these interpretations form the whole of 'enduring disruption' that constitutes this understanding and represent the meaning of living with chronic pancreatitis.

Conclusions: This is the first study in Ireland that has included those who live with chronic pancreatitis. Although the findings achieve idiographic generalisability only, they have some relevance for those living with the condition and those involved in their care. Primarily, this study, using a subjective lens, offers an alternative perspective to the previous quality of life research in chronic pancreatitis and presents a challenge to the emphasis on the management of the pathophysiological processes of disease and treatment that is decontextualised from the person's everyday living. It expands understanding of the complex and multidimensional experience that is living with chronic pancreatitis and reflects the efforts individuals make to strive for an acceptable life quality. The findings call for recognition of the condition at strategic and policy level in Ireland, if the needs of those living with it are to be met. Recommendations for service provision at strategic/policy, operational/local and professional levels are outlined in order to address the identified implications of the findings. Proposals for meeting the educational needs of those who care for people with chronic pancreatitis are suggested and propositions for the future direction of nursing research in this underdeveloped area of practice are made.

ACKNOWLEDGEMENTS

My sincere thanks to the participants and their families for agreeing to participate in this study, for giving so generously of their time and their thoughts and for allowing me to be part of their lives for a short period of time. Exploring their experiences with them had a profound effect on me as a person and a nurse and for that I am truly grateful.

Thank you to my academic supervisor Professor Cecily Begley who gave so willingly of her time and whose wise words, guidance and reassurance made this thesis possible.

My thanks also to the Consultant who supported the study and gave permission for access to the patients. Thank you to the Clinical Nurse Specialists and Data Controller who facilitated recruitment and acted as gatekeepers for the study.

Thank you to many of my colleagues who offered advice and support throughout. Particular thanks to Anita for the invaluable help and support with the preparing the final document.

I would like to extend my gratitude to Ben, Aisling and Mark for answering my many questions and providing practical help in managing the technology. I learned much from you.

To my dear friends Karen and Anne, thank you for being interested and for always being at the end of the phone to listen to my endless reflections.

Thank you to my sisters Mary and Fiona for your support during the difficult times and your unerring belief that I could do this.

To my boys, Daniel and Ben, the loves of my life, who make me laugh and stop me from taking myself too seriously. Finally, to my husband and friend, Andy, thank you for all those 'cups of tea'.

Table of Contents

DECLARATION	I
SUMMARY	II
ACKNOWLEDGEMENTS	IV
CHAPTER 1 – OVERVIEW OF THE STUDY	1
1.1 Introduction	1
1.2 Background to the study	1
1.3 Research question	3
1.3.1 <i>Aims and objectives</i>	3
1.4 Selecting hermeneutics	4
1.5 Structure of the thesis	6
CHAPTER 2 – LITERATURE REVIEW	9
2.1 Introduction	9
2.2 Literature Search	10
2.3 Chronic pancreatitis	10
2.4 Aetiology of Chronic Pancreatitis	13
2.4.1 <i>Prevalence and Incidence</i>	13
2.4.2 <i>Relationship with alcohol consumption</i>	14
2.4.3 <i>Genetic predisposition</i>	15
2.4.4 <i>Relationship with cigarette smoking</i>	16
2.4.5 <i>Idiopathic chronic pancreatitis</i>	16
2.4.6 <i>Other aetiological factors</i>	17
2.5 Classification of chronic pancreatitis	17
2.6 Natural/Clinical course/ Staging of chronic pancreatitis	22
2.6.1 <i>Staging</i>	22
2.6.2 <i>Clinical Features</i>	23
2.6.3 <i>Pain</i>	23
2.6.4 <i>Exocrine and endocrine insufficiency</i>	25
2.7 Additional complications	27

2.7.1	<i>Pancreatic cancer</i>	27
2.7.2	<i>Pseudocysts</i>	30
2.8	Prognosis	31
2.9	Health-related Quality of Life	32
2.10	Health-Related Quality of Life in Chronic Pancreatitis	33
2.10.1	<i>Long-term follow-up studies using Quality of Life Indicators</i>	34
2.10.2	<i>Evaluation/Comparison of interventions using Quality of Life Indicators</i>	35
2.10.3	<i>Evaluation/Comparison of interventions using Quality of Life Instruments</i>	36
2.10.3.1	Karnofsky Performance Status Scale	37
2.10.3.2	Spitzer Quality of Life Index	38
2.10.3.3	The Medical Outcomes SF-36	38
2.10.3.4	City of Hope Quality of Life (COH) Tool	39
2.10.3.5	Gastrointestinal Quality of Life Index (GIQLI)	41
2.10.3.6	Functional Assessment of Chronic Illness Therapy Instrument (FACIT)	42
2.10.3.7	European Organisation for Research and Treatment of Cancer Instrument (EORTC QLQ – C30)	44
2.10.4	<i>Evaluation of Quality of Life using Quality of Life Instruments</i>	48
2.11	Summary	53
2.12	Conclusion	54
CHAPTER 3	– PHILOSOPHICAL FRAMEWORK	56
3.1	Introduction	56
3.2	Hermeneutics	57
3.3	Schleiermacher	58
3.4	Dilthey	60
3.5	Heidegger	62
3.5.1	<i>Being</i>	63
3.5.2	<i>Understanding</i>	64
3.5.3	<i>Heidegger and this study</i>	66

3.6	Gadamer	68
3.6.1	<i>Understanding</i>	69
3.6.2	<i>Language</i>	70
3.6.3	<i>Dialogue/conversation</i>	70
3.6.4	<i>Horizon</i>	72
3.6.5	<i>Tradition</i>	72
3.6.6	<i>Prejudice</i>	73
3.6.7	<i>Fusion of horizons</i>	74
3.6.8	<i>Hermeneutic circle</i>	74
3.6.9	<i>Gadamer and this study</i>	75
3.6.9.1	Positioning the researcher	76
3.6.9.2	Engaging with the subject matter	77
3.6.9.3	Constructing meaning	78
3.7	Conclusion	80
CHAPTER 4	– METHODS	82
4.1	Introduction	82
4.2	Research question, aims and objectives of the study	82
4.3	Prejudices/Pre-judgements	83
4.4	Sample	86
4.5	Gaining Access	87
4.6	Exclusion criteria	87
4.7	Recruitment	87
4.8	Data collection procedures	89
4.8.1	<i>The Interview Process</i>	90
4.8.1.1	Gaining consent	90
4.8.1.2	Preparing for interviews	91
4.8.1.3	The interviews	92
4.8.1.4	Analysis during the interview process	96
4.8.2	<i>Diary-keeping</i>	97
4.8.3	<i>Interviews with family members</i>	97
4.8.4	<i>Reflection on the interview process</i>	99
4.9	Data Analysis	100
4.9.1	<i>Preparing for data analysis</i>	101

4.9.2	<i>Step 1 – Gaining understanding of the whole text</i>	103
4.9.3	<i>Step 2 – Detailed analysis of text</i>	105
4.9.3.1	Coding	106
4.9.3.2	Annotations	108
4.9.3.3	Memos	108
4.9.3.4	Conceptual mapping	109
4.9.4	<i>Step 3 – Expansion of the unity of the understood sense</i>	114
4.9.5	<i>Step 4 – Representing shared understandings</i>	116
4.10	Ethical Integrity	117
4.10.1	<i>Right not to be harmed</i>	117
4.10.1.1	Vulnerability	118
4.10.2	<i>Right to full disclosure</i>	123
4.10.3	<i>Right to self-determination</i>	124
4.10.4	<i>Right to privacy and anonymity</i>	125
4.10.5	<i>Informed consent</i>	128
4.11	Integrity of the study	129
4.11.1	<i>Balanced Integration</i>	131
4.11.2	<i>Openness</i>	132
4.11.3	<i>Concreteness</i>	134
4.11.4	<i>Resonance</i>	135
4.11.5	<i>Actualisation</i>	136
4.12	Conclusion	137
CHAPTER 5	– PRESENTATION AND DISCUSSION OF FINDINGS	139
ENDURING DISRUPTION – ‘PERPETUAL AND PERMANENT DISRUPTION’		139
5.1	Introduction	139
5.2	Literature Search	139
5.3	Enduring physiological disruption	141
5.3.1	<i>The Beginning – Initial salient disruption</i>	142
5.3.2	<i>Unpredictable daily disruptions</i>	145
5.3.2.1	Intrusive Pain	145
5.3.2.2	Gastrointestinal disturbances and food intolerance	149
5.3.2.3	Incapacitating fatigue	151
5.3.2.4	Loss of physical strength	153

5.3.2.5	Iatrogenic effects	154
5.3.2.6	Unexplainable symptoms	157
5.3.2.7	Complicating-co-existing pathologies	157
5.3.3	<i>Escalating/Salient physiological disruption</i>	160
5.3.4	<i>Summary</i>	163
5.4	Enduring social disruption	164
5.4.1	<i>Personal Relationships</i>	165
5.4.1.1	Altered personal relationships	165
5.4.1.2	Conflict in personal relationships	171
5.4.2	<i>Altered Social Relationships</i>	174
5.4.2.1	Social isolation and withdrawal	174
5.4.2.2	'Others' perception of illness'	180
5.4.3	<i>Altered economic circumstances</i>	185
5.4.3.1	Occupational Disruption	185
5.4.3.2	Financial vulnerability/constraints	189
5.4.4	<i>Summary</i>	191
5.5	Enduring psychological disruption – Disturbed Normal	193
5.5.1	<i>Being afraid</i>	195
5.5.2	<i>Loss</i>	198
5.5.2.1	Loss of healthy self	198
5.5.2.2	Loss of confidence/coherence	199
5.5.2.3	Loss of control	201
5.5.3	<i>Feeling down</i>	203
5.5.4	<i>Worry</i>	207
5.5.5	<i>Being angry</i>	209
5.5.6	<i>Summary</i>	214
5.6	Interpretation	216
CHAPTER 6 – PRESENTATION AND DISCUSSION OF FINDINGS		220
ENDURING DISRUPTION – 'TO COPE WITH' AND/OR 'TO TOLERATE'		220
6.1	Introduction	220
6.2	Coming to know	220
6.2.1	<i>Coming to know disrupted body</i>	222
6.2.1.1	Onset of physiological disruption	222

6.2.1.2	Pathways to diagnosis	224
6.2.1.3	Facilitating/constraining factors	228
6.2.2	<i>Coming to know chronic pancreatitis</i>	233
6.2.2.1	'Finding out'	234
6.2.2.2	Explaining	251
6.2.3	<i>Summary</i>	255
6.3	Adjusting/Managing	256
6.3.1	<i>Handling the pain</i>	258
6.3.2	<i>Modifying lifestyle</i>	263
6.3.2.1	Abstaining from alcohol	264
6.3.2.2	Adjusting diet	269
6.3.2.3	Prioritising demands	273
6.3.2.4	'Struggling to live well'	274
6.3.3	<i>Self-monitoring</i>	277
6.3.4	<i>Emotional Coping</i>	284
6.2.4.1	Adjusting expectations	285
6.2.4.2	Maintaining a sense of control	289
6.2.4.3	Distraction/Avoidance	291
6.2.4.4	Paralleling	292
6.2.4.5	Hope/Faith	293
6.3.5	<i>Drawing on social resources</i>	298
6.2.5.1	Practical support	298
6.2.5.2	Emotional support	300
6.3.6	<i>Interacting with the healthcare system</i>	305
6.3.7	<i>Summary</i>	312
6.4	Interpretation	314
6.5	Final Interpretation and Discussion	319
6.6	Conclusion	327
CHAPTER 7	– IMPLICATIONS AND RECOMMENDATIONS	330
7.1	Introduction	330
7.2	Implications	330
7.3	Recommendations for practice and service provision	334
7.3.1	<i>Service provision (Strategic and Policy Level)</i>	334

7.3.2	<i>Service provision (Operational and Local level)</i>	335
7.3.2	<i>Service provision (Professional Level)</i>	335
7.3.3	<i>Nurses working in clinical practice</i>	336
7.4	Recommendations for education	336
7.4.1	<i>In-service education</i>	336
7.4.2	<i>Nurse education</i>	336
7.5	Recommendations for research	337
7.6	Contribution to knowledge	338
7.7	Study Limitations	339
7.8	Summary and conclusion	341
	References	342
APPENDICES		381
Appendix 1:	Consultant approval to access sample for the study	
	382	
Appendix 2:	Institutional Ethics Approval to undertake the study	
	383	
Appendix 3:	Participant Information Sheet	384
Appendix 4:	'Expression of interest' slips	387
Appendix 5:	Informed Consent Form	388
Appendix 6:	Family Information Sheet	390
Appendix 7:	Family Informed Consent Form	392
Appendix 8:	Examples of Participants' stories	394
Appendix 9:	Examples of early Tree and Free Nodes	410
Appendix 10:	Feedback from School of Nursing & Midwifery Ethics Advisory Committee	413
Appendix 11:	School of Nursing & Midwifery Ethics Advisory Committee permission to proceed to Ethics approval	414

Table of Tables

Table 2.1: Marseille-Rome Classification of Pancreatitis	19
Table 2.2: Aetiologic risk factors associated with Chronic Pancreatitis: TIGAR-O Classification System	21
Table 4.1: Examples of Annotations	108
Table 4.2: Examples of Memos	109
Table 4.3: Family members 'living' with chronic pancreatitis	111
Table 4.4: Living with chronic pancreatitis – Thematic structure/hierarchy	111
Table 4.5: Free Nodes	114
Table 4.6: Criteria for Integrity in this study	131

Table of Figures

Figure 4.1: Steps of Data Analysis	103
Figure 5.1: Enduring physiological disruption	141
Figure 5.2: Critical attributes of chronic fatigue versus incapacitating fatigue in chronic pancreatitis	152
Figure 5.3: Enduring Social Disruption	164
Figure 5.4: Manifestation of enduring psychological disruption	194
Figure 5.5: Suffering in chronic pancreatitis	219
Figure 6.1: Coming to know	221
Figure 6.2: Adjusting/Managing	258
Figure 6.3: Transition in Chronic Pancreatitis	318
Figure 6.4: Chronic Pancreatitis – Enduring disruption	329

CHAPTER 1 – OVERVIEW OF THE STUDY

1.1 Introduction

The introductory chapter of this thesis provides an overview of this hermeneutic inquiry that has as its focus the meaning of living with chronic pancreatitis. It details the background to the study, which was considered pivotal to its purpose and significance and essentially constituted a reflective synthesis of clinical and personal experience, my convictions about the practice of nursing and my beliefs about the effect of illness on the quality of one's human existence. This is followed by an outline of the emergent research question and the aims and objectives of the study. A preliminary justification for the choice of hermeneutics as a philosophical underpinning for the study is presented. The chapter concludes with an outline of the structure of subsequent chapters of the thesis.

1.2 Background to the study

The idea for this study is located in my clinical experiences as a link lecturer providing support to student nurses who were allocated to clinical placements in a tertiary referral centre for Pancreatic/Biliary diseases in the United Kingdom. As a result of these experiences and significant encounters with patients, I undertook a study, in part fulfilment of a Masters in Nursing programme, exploring what it meant to be long-term 'nil by mouth'. The stimulus for the study was a discomfort that we as nurses, caring for patients who were 'nil by mouth', had little understanding of the magnitude of the individual's response to what was essentially part of a medical treatment regime. The findings of the study, although not generalisable beyond the small sample, appeared to support the initial suspicion that being 'nil by mouth' had a significant impact on the patients' quality of life, particularly their social and psychological well-being. Ultimately however, although it was possible to particularise some of the issues and attribute them to the 'nil by mouth' status, it became evident that decontextualising them from the patients' overall illness experience was a false separation.

My experiences of engaging with the participants in the 'nil by mouth' study and my continued encounters with patients in the unit, many of whom had been diagnosed with chronic pancreatitis, had a profound impact on my perceptions of the psychological and emotional care they received. Many had repeated and prolonged hospital admissions during which they experienced incapacitating treatment regimes. Furthermore, those with alcohol dependency were, at times, the subject of what I conceived to be devaluing remarks by healthcare professionals particularly if they were suspected of surreptitious alcohol consumption or if they refused help with alcohol related problems. My distress associated with what I considered to be a negative attitude to these individuals was intensified when I observed the progressive deterioration in their health over time and in the case of some, their death following an acute exacerbation of their chronic pancreatitis.

My reflections on these experiences led me to question how those with chronic pancreatitis live and manage this progressive and debilitating disease that has a long-term prognosis that has been described as dismal (Etemad and Whitcomb, 2001; Fitzsimmons et al., 2005). Chronic pancreatitis creates a life-long demand on health resources and necessitates fundamental life changes in those suffering from it. Throughout the illness trajectory there are significant and various challenges in relation to progression, treatment options and outcomes as well as potentially debilitating intractable pain, steatorrhea, malabsorption, malnutrition, diabetes mellitus, an increased risk of the development of pancreatic cancer and a range of other primary and secondary complications (Tyler Stevens et al., 2004).

There is a plethora of medical and surgical gastroenterological and pancreatic literature in relation to the clinical symptoms, treatments and interventions for chronic pancreatitis. However, more recently, there has been acknowledgement of the wider impact on psychological and social well-being and efforts have been directed at assessing health related quality of life using disease specific or adapted instruments (Pezzilli et al., 2004; Wehler et al., 2003; Wehler et al., 2004; Fitzsimmons et al., 2005). While this is an important development in acknowledging the nature and extent of the issues facing the person with chronic pancreatitis, the focus of much of the work is

on demonstrating the impact of various therapeutic interventions on perceived health related quality of life.

Despite these developments, little is known yet about how the person lives everyday with the condition and how it impacts on the decisions they make in their lives. Although people with chronic pancreatitis can spend significant periods of time in the acute hospital setting, in keeping with many chronic illnesses, much of the management is undertaken and maintained by the individual and their family in the community where everyday decision-making is grounded in the personal and social context of their lives. Furthermore, the effect and burden on immediate or close family members and informal carers is not known.

Therefore, it is my contention in undertaking this study that understanding how those with chronic pancreatitis and their families live is important in determining how their healthcare needs are met particularly in the face of a condition that is progressive, cannot be cured and whose symptoms can be made tolerable at best. Furthermore, despite the minimal reference to the care of those with chronic pancreatitis in the nursing literature, I believe nurses in acute and community settings are in a unique position to facilitate the development of strategies that maximise the potential for self-management of the condition.

1.3 Research question

Thus the emergent research question for the study is:

'what does it mean to live with chronic pancreatitis?'

1.3.1 Aims and objectives

The overall aim is to develop an understanding and construct a meaning of living with chronic pancreatitis and in so doing to:

- Illuminate the everyday contextualised and culturally situated lives of

the participants

- Explicate the meaning of living with chronic pancreatitis as a basis for understanding and interpretation by others
- Extract from the new understanding issues that may have implications for healthcare professionals and the practice of caring for those who live with chronic pancreatitis
- Identify recommendations for enhancing the care of those with chronic pancreatitis
- Develop recommendations for expanded understandings through further research

1.4 Selecting hermeneutics

The ultimate choice of Gadamerian philosophical hermeneutics to guide and direct this study was a process of discovery about how best to answer the research question and achieve the overall aims and objectives of the study. Initial consideration encompassed examination of alternative qualitative methodologies, particularly grounded theory and narrative inquiry. Narrative research, according to Creswell (2007), is rooted in a number of different social and humanities disciplines and has diverse forms and analytic processes. However, its underpinning aim is to depict a detailed story of a person's life or life experience. Typically, the approach is limited to a single person or a small number of people. Whilst there are parallels with the intention of the proposed research in that narrative involves active collaboration between the researcher and the participants with the potential for uncovering meaning, there is also a fundamental chronology in telling of the story/stories (Clandinin and Connelly, 2000). Since sequencing or time was not a key aspect of the intention of constructing the meaning of living with chronic pancreatitis, this approach was not adopted.

An examination of grounded theory was also undertaken to determine its potential applicability as an approach for this study. Its key premise is moving beyond description to the generation of a theory that is 'grounded' in the data (Holton, 2007). It has evolved over time from the original approach developed by Glaser and Strauss (1967) and spans a philosophical continuum from a

positivist to a constructionist stance (Holton, 2007; LoBiondo-Wood and Haber, 2006). Its goal is to generate a theory that accounts for what Glaser describes as a 'latent pattern of behaviour' that characterises human existence (1998:117). The researcher attempts to understand problems, actions and meaning from the perspective of the participants and generates a theory of how they process and resolve their main concerns (Glaser, 1998). It is the multiple and varied responses to resolution of their concerns that constitutes the latent pattern of social behaviour that ultimately forms the basis of the grounded theory. Whilst there was potential for the meaning of living with chronic pancreatitis to be captured through the generation of a substantive theory, the notion inherent in grounded theory data analysis of transcending the data and conceptualising to a higher level of abstraction was at variance with the intention of the present study. As indicated by Glaser (2001) the analyst in grounded theory focuses on organising ideas rather than a detailed presentation of data from which the ideas arise. Yet, in this study, I felt that in my efforts to illuminate the contextualised and culturally situated lives of the participants, staying close to and presenting thick description of the data rather than abstractions of it was fundamental.

Ultimately, two main factors pointed to hermeneutics, the science and art of interpretation (Palmer, 1969; Lawn, 2006) as offering an appropriate frame for the conduct of the study. Primarily, its focus is in keeping with the aim of hermeneutics, which in relation to human experiences, is to look for meanings embedded in everyday living and bring to the fore what is normally hidden (Lopez and Willis, 2004). Therefore, meaning is not always evident to those who participate in the inquiry but is constructed from the narratives produced by them.

This means that the researcher or interpreter is fundamental to the construction of meaning and is immersed in the process. In developing the question 'what does it mean to live with chronic pancreatitis?' I had identified that the subject matter was not only important to me but was something about which I had some knowledge emanating from my clinical and personal experiences in nursing. Therefore, my involvement was implicit and governed by my experiences. Moreover, it was because of these background

understandings that I was able to identify that, not only was my perspective limited, but there was another perspective also, that of those living with the condition, which made the subject worthy of study.

Thus, my focus was to explore the culturally situated and contextualised lives of those with chronic pancreatitis in order to gain an understanding of how they live. Through this, my horizon of understanding could be expanded and, in representing the meaning of living with the condition for others, perhaps the horizons of healthcare professionals who care for them could also be expanded.

1.5 Structure of the thesis

The remaining six chapters of this thesis address the substantive areas of the research process as it was undertaken in this study.

Chapter 2

Chapter 2 presents a preliminary review of the literature related to chronic pancreatitis and introduces the thesis that the complexity of the condition presents various and continuing quality of life challenges at each stage of its inexorable progression. The review begins with an explication of the aetiology, natural course, diagnosis and classification of the condition in order to situate the quality of life issues. The quality of life literature is examined and a critique of its limitations expounding the psychological and social impact on those with a diagnosis of chronic pancreatitis is offered.

Chapter 3

Chapter 3 focuses on the choice of philosophical hermeneutics after Gadamer (1976; 2004) as the philosophical framework, which underpins the study. In order to situate and understand the central concepts of Gadamer's hermeneutic, a brief exploration of the evolution of modern hermeneutics and its ontological turn in the 20th century is presented. A short overview of the work of early key philosophers such as Schleiermacher and Dilthey are outlined as they represent notable turning points in the development of hermeneutics but also symbolise important approaches to the problems of

interpretation. Some of the key concepts of the work of Martin Heidegger are also presented because of the central place he occupies in modern hermeneutics and because of the significant influence of his philosophy on Gadamer's work. A critical exposition of Gadamer's central concepts of 'understanding', 'language', 'dialogue/conversation', 'horizon', 'tradition', 'prejudice', 'fusion of horizons' and 'hermeneutic circle' is presented as they have relevance for the operationalisation of the study and offer some direction for how the researcher is positioned, how the subject matter might be engaged and how meaning might be constructed.

Chapter 4

The focus of chapter 4 is the operationalisation and conduct of the study into the meaning of living with chronic pancreatitis. This includes a reiteration of the research question and aims and objectives following which my prejudices related to the subject matter are delineated. Practical endeavour related to recruitment, access, sampling, data collection and data analysis are addressed. Pertinent ethical issues, designated as ethical integrity are explored as are the rationale for and selection of criteria for judging the overall integrity or rigour of the study. Through reflexivity, I attempt to represent the challenges of this inquiry and how I endeavoured to meet them. In addition, chapter 4 includes my early understanding of the meaning of living with chronic pancreatitis that is conceptualised as 'Enduring Disruption'. 'Enduring' has a two-fold meaning. It is an adjective to describe the perpetual or permanent nature of the disruption and comprises physiological, social and psychological elements. Secondly, it is a verb 'to endure' that is, 'to cope with' and/or 'to tolerate'. In this sense, enduring refers mainly to how the participants and their families cope with the perceived restrictions arising from the condition, their capacity to tolerate them and the strategies developed to manage them.

Chapters 5 and 6

Chapters 5 and 6 comprise the presentation and discussion of findings that essentially represent the final stages of the process of analysis depicted as explication of the expanded meaning of the whole and representing shared understandings between the participants and me.

Chapter 5 examines the three unifying categories of enduring physiological disruption, enduring social disruption and enduring psychological disruption that symbolise enduring (permanent or perpetual) disruption and interpreted to represent 'suffering'. In Chapter 6, the meaning of 'endure', 'to cope with' and/or 'to tolerate' discusses how the participants and their families 'come to know', and 'adjust/manage' through the development of self-management strategies within an overall transition from 'well' person to a person who lives with chronic pancreatitis. Together, these form the whole of the meaning of living with chronic pancreatitis. These chapters conclude with a final interpretation and critical discussion of the key findings.

Chapter 7

The final chapter of the thesis discusses the implications and recommendations of chronic pancreatitis as Enduring Disruption for service provision, practice, education and research.

CHAPTER 2 – LITERATURE REVIEW

2.1 Introduction

This preliminary literature review critically examines the plethora of literature related to chronic pancreatitis and demonstrates that such a diagnosis has a significant impact on quality of life. It implies long standing disease both in pathogenesis and effect with attendant morbidity and consumption of health care resources. The thesis is presented that the complexity and dynamism of the aetiology, natural course, diagnosis, treatment and outcomes of the condition presents various and continuing quality of life challenges at each stage for those living with it. There have been numerous calls within the chronic pancreatitis literature for the development of a validated Quality of Life assessment instrument to be used as part of the treatment and outcome of chronic pancreatitis. Work has been undertaken in recent years on the development of such an instrument but it is evident that the sheer complexity of the condition renders evaluation difficult. Of particular relevance to this study is the recent acknowledgement that the wider impact of chronic pancreatitis on patients' psychological and social well-being and the burden of living with the condition is recognised (Keith, 2003), but has not been well documented (Fitzsimmons et al., 2005).

The review begins with an exposition of the aetiology, natural course, diagnosis and classification of the condition in order to contextualise and provide a background for the study. Subsequently, the emergence in the literature of quality of life and health-related quality of life as issues of importance to the care of those with chronic pancreatitis is examined.

The preliminary literature presented here was collected in 2005 before the study began and its purpose was to contextualise and situate the research question by determining the current knowledge related to chronic pancreatitis and its impact on quality of life. Furthermore, it was intentionally limited so that pre-conceptualisation of the meaning of living with chronic pancreatitis did not take place. A subsequent literature search was undertaken following completion of Stage 3 of the data analysis, where the process of

interpretation and gaining understanding is further facilitated by reference, in Chapters 5 and 6, to pertinent and indicative literature that is related to the findings of the study.

2.2 Literature Search

Several online databases were used in the initial search of the literature from 1990 to the present and using 'chronic pancreatitis', as the primary search term. These included PubMed, Cinahl (Cumulative Index to Nursing and Allied Health), Cochrane Database, Internurse, Proquest, the British Journal of Nursing Index and Blackwell Synergy. Relevant literature was almost exclusively located within the medical domain with the majority appearing in American and European Pancreas and Gastroenterology and Surgery Journals. A medical dictionary, bibliography and annotated research guide on chronic pancreatitis was also procured and assisted in ensuring that pertinent and relevant studies were not omitted. At this stage, publications that addressed aetiology, natural course, staging, diagnosis and classification of chronic pancreatitis were sourced. Major texts and related government publications were also obtained.

Following the initial retrieval of literature, further related search terms were entered and included 'chronic pancreatitis' in conjunction with 'quality of life', 'chronic illness', 'health-related quality of life', 'subjective health status' and 'patient-based outcome'.

Search engines such as Google were used to locate and access original health-related quality of life instruments. Sourced literature included studies that purported to have examined quality of life and chronic pancreatitis.

2.3 Chronic pancreatitis

According to Gavaghan (2002:1110), the pancreas is known as the 'hermit of the abdomen'. This sense of its reclusive nature is largely attributable to its location in the abdomen and the attendant difficulties with identification and diagnosis of pancreatic pathologies (Gorman, 2003). The pancreas could be said to draw attention to itself only at the advanced stages of disease and

dysfunction. The metaphor of the pancreas as a hermit is a useful one as the knowledge and understanding of its structure, function and purpose is limited within the general population and to a certain degree among healthcare professionals. Pancreatic disease remains relatively uncommon and as Tinto et al (2002) state, an annual incidence of 20 per 100,000 means that a typical General Practitioner with a practice of 1800 patients would only expect to see one case every 3 years. However, the inpatient management of patients with chronic pancreatitis demands a disproportionate amount of time and resources compared to most other conditions. Furthermore, a diagnosis of chronic pancreatitis creates a life-long demand on health care and social resources as the impact can be significant.

The presence of the symptoms of chronic pancreatitis may be debilitating leading to concomitant psychosocial problems, loss of work, narcotic addiction and consumption of health-care resources (Tyler Stevens et al., 2004). Keith (2003) also alludes to the issue of dependence where transference from alcohol to narcotics is not uncommon. He argues that although the primary role of the surgeon is to treat pain, that alone is not fully adequate to rehabilitate the individual with what he describes as pancreatic insufficiency, diabetes and social displacement. Total treatment demands multidirectional therapies. Even with such approaches, Etemad and Whitcomb (2001) claim the prognosis for improvement in those diagnosed with chronic pancreatitis today is dismal.

These life-changing events tend to occur in a population whose mean age is 40-50 years although there have been incidences of chronic pancreatitis developing in patients under the age of 30 (Bornman and Beckingham, 2001; Mitchell et al., 2003). In a study of hospital admissions between 1989/1990 and 1999/2000, admission rates for chronic pancreatitis doubled over the period of the study, from 2049 to 4396 and the age-standardised rates were consistently higher in males than females with admission peaks in the 35-44 and 45-54 age groups (Tinto et al., 2002). Gorelick and Roblez-Diaz (2002) suggest that gender may affect the risk of developing pancreatitis and that the mean alcohol intake for men who develop pancreatitis is about twice that of women. This appears to suggest that a susceptible female is likely to

develop pancreatitis with a much lower ethanol intake. In Tinto et al's (2002) study, a rise in the number of females consuming more than 14 units of alcohol per week across all age groups and an increase in their admission for acute pancreatitis with alcohol aetiology was evidenced. There has been a suggestion, albeit controversial, of a correlation between repeat attacks of acute pancreatitis and the subsequent development of chronic pancreatitis (Di Sebastiano et al., 2003).

There appears to be general agreement in the literature that chronic pancreatitis is a chronic clinical disorder characterised by permanent damage to the pancreas, the development of histological evidence of inflammation and fibrosis and, generally many years later, followed by progressive exocrine and endocrine insufficiency and sometimes calcification (Steer et al., 1995; Mergener and Baillie, 1997; Talamini et al., 2001; Uomo, 2002; Mitchell et al., 2003; Otsuki, 2003; Strate et al., 2003; Tyler Stevens et al., 2004; Cavestro et al., 2005).

Uomo (2002) claims this type of definition distinguishes acute first-onset pancreatitis from advanced chronic pancreatitis. Despite this, Steer et al (1995:1482) argue that chronic pancreatitis remains an 'enigmatic process of uncertain pathogenesis, unpredictable clinical course and unclear treatment'. Tyler Stevens et al (2004) corroborate the view of an uncertain pathogenesis. In their evidence-based review of the past theories of pathogenesis and recently developed mechanisms of pancreatic fibrosis and new pathogenic concepts, they highlight how the pathogenic mechanism of chronic pancreatitis has remained elusive. Their critique outlines the tenets of four traditional and central theories for explaining the pathogenesis of chronic pancreatitis: toxic-metabolic, oxidative stress, stone and duct obstruction and necrosis-fibrosis including their short-comings. They also explore more recent hypotheses that include the notion of chronic pancreatitis as an autoimmune 'duct destroying' disease (Cavallini et al., 1998) and present the SAPE (Sentinel Acute Pancreatitis Event) that appears to unify traditional theories of pathogenesis as well as incorporating the more recent knowledge about the molecular and cellular mechanisms. Whilst the detail of each of these theories falls outside the remit of this review, the significance of Tyler Stevens et al's

work is that it clearly identifies the medical challenges presented by chronic pancreatitis. Each theory attempts to propose a unifying view and each has a compelling and interesting stance despite possible deficiencies. It is more likely, they claim, that the answer lies in all of the models with each 'providing one piece of the puzzle' (Tyler Stevens et al., 2004:2266); that is, diverse aetiologies lead to chronic pancreatitis through unique pathways.

2.4 Aetiology of Chronic Pancreatitis

The aetiology of chronic pancreatitis includes alcohol, nutritional factors, pancreatic duct obstruction, cystic fibrosis, hereditary and idiopathic causes (Bornman and Beckingham, 2001). Tyler Stevens et al (2004) categorise these as toxic and metabolic, idiopathic, genetic, autoimmune, recurrent and severe acute pancreatitis associated with chronic pancreatitis and obstructive whilst Strate et al (2003) simply divide them between alcohol-induced and non-alcohol induced chronic pancreatitis.

2.4.1 Prevalence and Incidence

According to Tandon et al (2002), the estimated prevalence of chronic pancreatitis in Western industrialised countries is approximately 10-15/100,000 population with an annual incidence of 3.5-4/100,000 population. However, they also claim that epidemiological data regarding the magnitude of chronic pancreatitis is lacking in many areas of the world. According to the Economic and Social Research Institute (2005) prevalence data are not available in Ireland but the United Kingdom has an annual incidence of about 1 person per 100,000 with a prevalence of 3/100,000, which may be comparable (Bornman and Beckingham, 2001). Using the ICD-9 codes, it was possible, following a personal request to the Economic and Social Research Institute (ESRI), to extract data about hospital discharges in Ireland with a primary or secondary diagnosis of chronic pancreatitis. These were 680 and 622 in 2003 and 2004 respectively (Economic Social Research Institute, 2005). Although these statistics are useful in highlighting the existence of this group of patients, they are limited in that they do not offer an indication of prevalence or true spectrum of the condition. They cannot distinguish the

number of admissions per individual patient nor is it possible to ascertain the number of patients who have not been hospitalised in any one year.

In the years 1995-2004 an average of 3 patients per year had 'chronic pancreatitis' recorded as the cause of death in Ireland (Central Statistics Office, 2005). However, mortality statistics are inadequate as they do not reflect deaths recorded from co-morbidities or complications arising in people with chronic pancreatitis. Internationally, extra-pancreatic and pancreatic malignancies, cirrhosis, cardiovascular disease and complications of diabetes mellitus are the leading causes of death in these patients (Cavallini et al., 1998; Malka et al., 2000; Malka et al., 2002; Otsuki, 2003).

Etemad and Whitcomb (2001) believe the reported incidence, prevalence and manifestations of chronic pancreatitis with overt disease underestimates its true spectrum. They go on to state that the improved sensitivity of diagnostic tests and changes in alcohol consumption throughout the world has led many to believe its incidence is far higher than originally thought. In most countries, the most common or dominant cause of chronic pancreatitis is reported to be alcohol abuse, which accounts for between 60-70% of all cases (Steer et al., 1995), although Bornman and Beckingham (2001) claim this is between 80-90%.

2.4.2 Relationship with alcohol consumption

The relationship between alcohol and the development of chronic pancreatitis is well known. Bornman and Beckingham (2001) and Otsuki (2003) state that there is no uniform threshold for alcohol toxicity although a pattern of heavy drinking over many years (>10 years) correlates with the development of chronic pancreatitis. Reports on the amount of alcohol intake vary slightly from 150-175mg/day (Tandon et al., 2002) to 150-200mg/day (Bornman and Beckingham, 2001). The latter claim the pattern of intake (regular or binge) or the type of alcohol (spirits, wines, beers) does not appear to impact.

There is some suggestion that the incidence of chronic pancreatitis in the population may parallel rates of alcohol consumption (Tandon et al., 2002; Tinto et al., 2002; Otsuki, 2003). Many believe there has been a rise in the

frequency of chronic pancreatitis in recent years. Ramstedt's (2004) comparative analysis from 14 western countries suggests that an increase in per capita alcohol consumption of 1 litre is followed by an increase of pancreatic mortality of 5-15% in most countries. This increase appears to be more significant in Northern European countries than Southern European. Ramstedt posits that this difference could be explained by the propensity for binge drinking in Northern European countries including Ireland.

The Strategic Task Force on Alcohol (Department of Health and Children, 2004b) cite a study of the Irish drinking habits in 2002 (n=1069) (Ramstedt and Hope, 2005) that shows Ireland has the highest reported consumption per drinker and the highest level of binge drinking in comparison to adults in other European countries. In the same report, pancreatitis is named along with liver cirrhosis and categorised in gastrointestinal conditions that constitute 7.8% of the global burden of disease attributable to alcohol. The healthcare costs of alcohol related problems in Ireland were estimated to be 279 million euro in 2001 and 433 million euro in 2003 constituting a significant rise of 154 million euro (Department of Health and Children, 2004b). However, the report does not offer a break down of the costs and little mention is made of the long-term harmful effects of chronic pancreatitis.

Current government policy reflects deep-seated concerns about attitudes to alcohol and the incidence and prevalence of alcohol problems in our society. A previous survey indicated that males between the ages of 15 and 44 years have a poor knowledge of limits for safe alcohol consumption and are indifferent to the health effects of excess alcohol intake. Yet in respect of chronic pancreatitis, it is the 15-25 age-group that is at high-risk (Health Promotion Unit Department of Health and Children and Centre for Health Promotion Studies National University of Ireland Galway, 2003).

2.4.3 Genetic predisposition

Gullo (2005) argues that alcohol is a primary or leading exogenous aetiopathogenetic factor in the development of chronic pancreatitis. A leading endogenous factor, however, is genetic predisposition. The importance of genetics in the development of chronic pancreatitis is stressed by the

evidence that only a minority of people with alcohol abuse (approximately 10%) develop chronic pancreatitis (Hayakawa et al., 2002; Gullo, 2005). This led Etemad and Whitcomb (2001) to propose that alcohol is a co-factor in the development of chronic pancreatitis in susceptible human beings and that there is no proof that alcohol consumption causes chronic pancreatitis independent of more important and dominant genetic or environmental factors whose identities currently remain elusive.

2.4.4 Relationship with cigarette smoking

In recent years cigarette smoking has also been implicated as a toxin in the development of pancreatitis especially alcohol associated disease. However, Gullo (2005) regards this as a secondary exogenous factor. Morton et al (2004) state that some suggest the link might be spurious, confounded by the known alcohol-smoking relationship. Many of those who have alcoholic pancreatitis are also heavy smokers. Despite this, they conclude that cigarette smoking is a risk for alcohol-associated pancreatitis independent of the alcohol-smoking relationship. They also found, in their sample of 439 people, a possible relationship with the development of idiopathic pancreatitis. In a separate study in five countries (n=934) Maisonneuve et al (2005) found that cigarette smoking was associated with an earlier diagnosis of chronic pancreatitis and with the appearance of calcifications and diabetes, independent of alcohol consumption.

2.4.5 Idiopathic chronic pancreatitis

Between 30-40% of patients who develop chronic pancreatitis do not appear to have an apparent underlying cause. These are classified as having idiopathic chronic pancreatitis. New discoveries of genetic, immune-related and environmental risk have caused this category to diminish in recent years (Tyler Stevens et al., 2004). Despite this, the figure for patients with chronic pancreatitis who do not possess any risk factor remains at between 10-30%. Although a rare condition Tyler Stevens et al (2004) posit that a substantial portion of patients diagnosed with idiopathic chronic pancreatitis may also be accounted for by what is known as autoimmune chronic pancreatitis. Autoimmune chronic pancreatitis may occur in isolation or in connection with

other autoimmune diseases but it is likely that its pathogenesis is related to an immune-mediated attack on the ductal cells of the pancreas.

2.4.6 Other aetiological factors

Metabolic conditions that have been associated with acute and chronic pancreatitis include hypercalcaemia and chronic renal failure but again the specific pathogenesis is not known. Cystic fibrosis and hyperparathyroidism are occasionally associated with chronic pancreatitis. There have also been some significant developments in the genetic mechanisms for inherited chronic pancreatitis, for example the cystic fibrosis gene, which have led to insights into the genetics of pancreatic disease.

Nutritional or tropical pancreatitis is confined largely to impoverished areas of Africa and Asia and according to Steer et al (1995) is a poorly characterised heterogeneous disease. There has been some claim to a link with protein (kwashiorkor) and trace element malnutrition with additional uptake of tapioca and cassava toxins (Bornman and Beckingham, 2001; Strate et al., 2003). However, Tandon et al (2002) reject the assumption that it is associated with large consumption of cassava.

Lesions that obstruct the pancreatic duct and cause chronic pancreatitis include post-traumatic ductal strictures, pseudocysts, mechanical or structural changes of the pancreatic-duct sphincter and periampullary tumours. Pancreatic divisum, a developmental defect in which the head and body of the pancreas are separate glands, can cause a relative obstruction to the flow of pancreatic juice at the lesser papilla thus leading to chronic pancreatitis.

2.5 Classification of chronic pancreatitis

The complexity of the disease process and the diversity of aetiologies have implications for the diagnosis and classification of chronic pancreatitis. Etemad and Whitcomb (2001) argue that the recent advances in molecular and genomic technologies and progress in pancreatic imaging techniques provide remarkable insight into genetic, environmental, immunological and pathological factors that lead to chronic pancreatitis. However, they also

argue that in order to translate these advances into clinical practice a re-assessment of diagnosis, classification and staging of the condition is necessary. Between the two extremes of first-onset and advanced chronic pancreatitis, classification is difficult, a view supported by Tinto et al (2002) who purport there are no universally agreed diagnostic criteria for differentiation between acute relapsing and chronic pancreatitis. Furthermore, there is no agreed gold standard for the diagnosis of chronic pancreatitis and early chronic pancreatitis is particularly difficult.

The importance of classification is highlighted by Uomo (2002) who argues that its primary function is to provide a common language for those caring for patients. In other words, it would provide a means of definitively identifying what is and what is not chronic pancreatitis. In addition, re-examining the epidemiology of chronic pancreatitis using criteria concomitant with the advances in knowledge would assist in determining preventative health care policy. Thus, Etemad and Whitcomb (2001) claim that a classification system should include aetiology, pathogenesis, structure, function and clinical status in one overall scheme. The consensus is that the available systems do not meet all of these criteria (Tandon et al., 2002; Uomo, 2002).

Uomo (2002) claims the available classification systems reflect the state of the art at the time of their development. For example, the Marseille classification as described by Sarles (1965) and its subsequent revisions, the Marseille-Rome classification of 1988 (Sarles et al., 1989), defined the differentiation between the acute and chronic forms of pancreatitis, which Keith (2003) claims is its most important feature (Table 2.1). Acute disease, it was argued, characterised by single or repeated attacks was a self-limiting clinical entity and if a recognised causative factor was removed then the disease would not re-occur. It was also recognised that exocrine and endocrine function of the gland was not permanently affected by an episode of acute pancreatitis. Etemad and Whitcomb (2001) consider the Marseille and Marseille-Rome systems more useful in defining chronic pancreatitis than serving as a classification system. Moreover, they propose these classifications should now be considered out-dated and inadequate

considering the improved understanding of the pathophysiology and natural history over the last fifteen years.

Table 2.1: Marseille-Rome Classification of Pancreatitis

Acute Pancreatitis
Chronic calcifying pancreatitis
Chronic obstructive pancreatitis
Chronic inflammatory pancreatitis

The Cambridge classification system of 1984 (Sarner and Cotton, 1984) uses imaging features to provide a grading and severity system. It also differentiates between acute and chronic pancreatitis and notes that a single episode of acute pancreatitis may have implications for pancreatic morphology and function. However, it does not distinguish between different forms of chronic pancreatitis on the basis of aetiology nor does it aid in clinically distinguishing patients or the functional abnormalities associated with those specific aetiologies. Thus, the Cambridge classification system is seen as more useful as a staging system once the diagnosis has been made rather than as a system for classifying the aetiologies of chronic pancreatitis (Etemad and Whitcomb, 2001; Uomo, 2002).

Amman et al (1999) proposed the Zurich classification system which is specific to the alcoholic form of chronic pancreatitis. It considers diagnosis, aetiology, clinical staging and pain profile separately and according to Uomo (2002) emphasises the dynamism of the disease; however it has not been widely accepted. The Japan Pancreas Society also developed a classification for chronic pancreatitis which is designed to standardise the diagnostic criteria but it lacks the aetiological and pathogenetic features. Therefore it is seen as only partially useful in the clinical setting. Keith (2003), identifies that the International Classification of Diseases of the World Health Organisation has, under the heading of 'Pancreatitis', a listing of recognised variants of acute and chronic pancreatitis. He argues that the list contains most of the descriptors from the Marseille and Cambridge classifications and that it could be adopted, with modifications, to facilitate standardisation of national and international health records for use by professional caregivers and clinical

investigators. However, support for his view could not be found in the literature.

A more contemporary proposal is that of Etemad and Whitcomb's (2001) who claim the recent advances in genetics and technology have provided possibilities for accurate and early identification of risk factors leading to chronic pancreatitis. Their system, entitled the TIGAR-O Classification system, is proposed to replace the previous Marseille systems (Table 2.2).

It outlines the major risk factors associated with the development of chronic pancreatitis according to toxic-metabolic causes, idiopathic, genetic, autoimmune, recurrent severe-acute pancreatitis-associated chronic pancreatitis and obstructive pancreatitis. They claim the system is based roughly on the prevalence of each aetiology and that each class has implications for potential treatment (Etemad and Whitcomb, 2001). Tyler Stevens et al (2004) interpret it as proposing risk modifiers, rather than aetiologies, that may interact in any one patient through unique mechanisms. Therefore, a patient is classified according to the factor most strongly associated with pancreatitis in that person.

They continue that, with few exceptions, the aetiology of most cases of chronic pancreatitis is only partially known. For example, they claim that excessive alcohol consumption alone does not cause chronic pancreatitis in animals or humans. Thus other genetic or environmental factors yet to be identified must be present before alcoholic pancreatitis develops; therefore they pay special attention to genetic testing.

Genetic and molecular analysis is seen by Etemad and Whitcomb (2001) as being important in the future for evaluation of pancreatic disease. They believe identification of genetic mutations will provide key information on the risk of developing pancreatitis and will assist in the early diagnosis of pancreatic disease as well as aid our understanding of gene-environmental interactions. Furthermore, mutation identification will assist with the aetiology of the disease and provide a system of rational classification. Knowledge of the functional impact of gene defects may lead to new therapeutic

interventions and may also provide important answers for patients who are asking 'why' they develop pancreatitis. Finally, they claim molecular classification will help clarify the progression and prognosis of pancreatitis.

Table 2.2: Aetiologic risk factors associated with Chronic Pancreatitis: TIGAR-O Classification System

TIGAR-O Classification system	
Toxic-metabolic	Alcoholic Tobacco smoking Hypercalcaemia Hyperparathyroidism Hyperlipidaemia (rare & controversial) Chronic renal failure Medications Phenacetin abuse (possibly from chronic renal insufficiency) Toxins Organotin compounds (e.g. DBTC)
Idiopathic	Early onset Late onset Tropical Tropical calcific pancreatitis Fibrocalculous pancreatic diabetes Other
Genetic	Autosomal dominant Cationic trypsinogen (Codon 29 & 129 mutations) Autosomal recessive/modifier genes CFTR mutations SPINK1 mutations Cationic trypsinogen (Codon 16, 22, 23 mutations) α^1-Antitrypsin deficiency (possible)
Autoimmune	Isolated autoimmune chronic pancreatitis Syndromic autoimmune chronic pancreatitis Sjögren syndrome – associated chronic pancreatitis Inflammatory bowel disease – associated chronic pancreatitis Primary biliary cirrhosis – associated chronic pancreatitis
Recurrent and severe acute pancreatitis	Postnecrotic (severe acute pancreatitis) Recurrent acute pancreatitis Vascular diseases/ischaemia Postirradiation
Obstructive	Pancreatic divisum Sphincter of Oddi disorders (controversial) Duct obstruction (e.g. tumour) Pre-ampullary duodenal wall cysts Post-traumatic pancreatic duct scars

(Etemad and Whitcomb, 2001)

Etemad and Whitcomb's thesis is that determination of aetiology continues to grow in importance as more forms of chronic pancreatitis are identified at

earlier stages. The lack of precise classification and stratification systems continues to hinder comparison of clinical studies and frustrates attempts to design new trials for assessing diagnostic or therapeutic interventions (Etemad and Whitcomb, 2001). They propose that knowledge of aetiology is central to clinical and pathological studies, multifactorial analysis, understanding of the natural course and clinical history of each of the disorders that produces chronic pancreatitis and the development of preventative and therapeutic strategies. Their conclusion is that the adoption of a classification system such as TIGAR-O acknowledges the multiple aetiologies that predispose individuals to chronic pancreatitis. They argue that once a diagnosis of chronic pancreatitis is made and the aetiologies determined, staging of the disease becomes important. However, the expertise and technology in respect of staging is also considered limited.

2.6 Natural/Clinical course/ Staging of chronic pancreatitis

2.6.1 Staging

Staging the severity of chronic pancreatitis is rather crude, generally being categorised as mild, moderate or severe and is accomplished by pathological, functional or structural evaluation (Etemad and Whitcomb, 2001). A four-stage classification is generally used in Japan (Otsuki, 2003) and defined as latent, compensatory (early), transitional and non-compensatory (advanced) stages. This staging has been developed using clinical signs and symptoms and pancreatic function. The latent period which appears to correspond with Steer et al's (1995) sub-clinical phase is of variable duration (5-20 years) and precedes the onset of symptoms. In alcoholic chronic pancreatitis, this phase is often characterised by a long asymptomatic phase of mild to heavy drinking. However, even at this early stage, morphological findings such as inflammatory infiltration of pancreatic tissue, fibrosis, atrophy of the acinar cells, calcifications and pancreatic duct strictures can be found even without clinical symptoms (Strate et al., 2003). In the early (compensatory) stage, patients experience recurrent attacks of abdominal pain and/or tenderness. Serum and urinary levels of pancreatic enzymes are raised during the attacks but the endocrine and exocrine function of the pancreas is well preserved. The advanced or non-compensatory phase is characterised by the development of

pancreatic calculi with a gradual deterioration of pancreatic function. The loss of endocrine function, however, seems to occur later than exocrine dysfunction. Strate et al (2003) describe the gland as globally insufficient at this stage. Otsuki's (2003) suggestion that the abdominal pain and frequency of attacks diminishes with the progression of the disease remains highly controversial and is contested by Gupta and Toskes (2005). The pain may subside although this is an exception (Strate et al., 2003). The transitional phase is described as containing clinical features of the compensatory and non-compensatory phases.

2.6.2 Clinical Features

The pathological changes associated with chronic pancreatitis result in abdominal pain (Lankisch, 2001; Strate et al., 2003; Cunha et al., 2004; Gupta and Toskes, 2005), malabsorption (Vaona et al., 1997; Dumasy et al., 2004; Forsmark, 2004), steatorrhoea (Steer et al., 1995; Keith, 2003; Petersen and Forsmark, 2003), weight loss (Ambrecht, 2001; Tyler Stevens et al., 2004) and in the later stages possibly diabetes mellitus (Morillas Arino et al., 1997; Papa, 1998; Malka et al., 2000; Malka et al., 2002; Angelopoulos et al., 2005). There is also an increased risk of pancreatic pseudocysts and pancreatic cancer (Etemad and Whitcomb, 2001; Howes and Neoptolemos, 2002; Cavestro et al., 2003; Mitchell et al., 2003; Otsuki, 2003; Whitcomb, 2004) with some reports of sinistral portal hypertension due to splenic vein thrombosis, obstructive jaundice and duodenal stricture (Alexakis et al., 2004; Kakizaki et al., 2005).

2.6.3 Pain

The management and treatment of patients with chronic pancreatitis and associated complications remains a major challenge (Strate et al., 2003; Cunha et al., 2004) and can be frustrating for both patients and clinicians (Gupta and Toskes, 2005). Pain either persistent or episodic is the symptom that most often requires treatment (Steer et al., 1995) and it has been described as the most distressing symptom for the patient and in many instances leads to considerable analgesic abuse before a specialist is even consulted. The pain can be so intense and long-lasting that follow-up is

difficult and many patients become addicted to the narcotics that are prescribed (Tyler Stevens et al., 2004). Moreover, attacks of acute pancreatitis can be superimposed on the pattern of chronic pain (Di Sebastiano et al., 2003).

Amman et al (1999) classify the pain of chronic pancreatitis as Type A, which refers to recurrent episodic pain suggestive of an acute exacerbation or Type B, which is continuous pain. The difficulty appears to be a continued poor understanding of the pathogenesis of the pain. An association with perineural inflammation, increased pressure in both large and small ducts and in the pancreatic parenchyma, an abnormal feedback mechanism or pancreatic carcinoma with duct obstruction has been suggested (Gupta and Toskes, 2005). In addition, these patients may develop secondary complications such as pseudocysts, duodenal or duct obstruction that may exacerbate their pain (Bornman et al., 2003; Gupta and Toskes, 2005). Furthermore, Gupta and Toskes (2005) claim patients with chronic pancreatitis have a high incidence of dysmotility that may cause or worsen pain and may be aggravated by simultaneous narcotic use.

Pain, therefore, is the cardinal symptom in chronic pancreatitis and is classically located 'in the epigastrium, radiates to the back, is associated with oral intake, nausea, vomiting and is relieved by sitting forward' (Gupta and Toskes, 2005:492). Patients may avoid eating, as it tends to exacerbate the pain, leading to severe weight loss and possible malnutrition. If patients have an accompanying steatorrhoea these symptoms can be significant (Bornman and Beckingham, 2001).

However, its presentation varies significantly from patient to patient and its management tends to dominate the clinical setting due to its complexity, intractability and resistance to most medical and endoscopic therapies (Etemad and Whitcomb, 2001). Furthermore, even following surgical management, the pain often recurs (Etemad and Whitcomb, 2001). Current therapeutic concepts therefore aim at alleviating pain and managing organ complications. However, there are polarised views among the surgical community as to the correct surgical management of pain in chronic

pancreatitis (Morrison et al., 2002). Albeit unintentional, this can lead to further distress and insecurity for patients.

2.6.4 Exocrine and endocrine insufficiency

The gradual destruction of the pancreatic parenchyma leads to impairment of exocrine and endocrine function but clinical signs of malabsorption and steatorrhoea only appear after significant destruction of between 80-90% (Dumasy et al., 2004). In previous natural history studies of chronic pancreatitis (Lankisch et al., 1993; Layer et al., 1994) steatorrhoea and weight loss provide the clinical evidence of advanced structural damage of the pancreas. However, exocrine insufficiency is not a universal consequence of chronic pancreatitis (Forsmark, 2004) although it appears that those with alcoholic chronic pancreatitis are more prone and it tends to occur at between 5-10 years of onset of the disease.

What is significant about the development of steatorrhoea is that it may be an end point of a gradual process of nutritional depletion. It has been suggested more recently, that there may be a window between the actual development of exocrine insufficiency and clinical evidence of its existence (Dumasy et al., 2004; Forsmark, 2004). It is argued that in this window patients may develop nutritional deficiencies that are harmful. In their screening study of 60 patients, Dumasy et al (2004) suggest that clinical steatorrhoea as a predictor of exocrine dysfunction had a sensitivity of only 38%. They purport that malabsorption occurs gradually in chronic pancreatitis and even mild malabsorption without clinical signs can have a negative effect on weight loss. They propose early screening even in the absence of the clinical signs and argue that early enzymatic treatment for malabsorption will assist with body mass index annual loss. They support this proposal by outlining the 0.5kg/m²/year loss in patients on enzyme replacement compared with double that in patients who were not treated. This study was not a randomised trial and therefore it is not possible to state clearly whether the weight loss was due to lack of pancreatic enzymes or some other factor associated with chronic pancreatitis such as reduced calorie intake due to pain after meals in the early stages of the disease or the impairment of endocrine and exocrine function in the later stages. Nonetheless, the study presents a case for early

screening and treatment for fat malabsorption particularly given that other adverse effects exist, such as osteoporosis due to malabsorption of Vitamin D (Forsmark, 2004). Finally, the presence of pale, loose offensive stools and the possibility of developing faecal incontinence in severe cases compound the difficulties for the patient both psychologically and socially.

Endocrine insufficiency manifests itself by the development of diabetes mellitus, which is regarded as a major late consequence of chronic pancreatitis, is an independent risk factor for mortality and impacts on quality of life (Malka et al., 2000). There have been varying reports on the incidence of diabetes mellitus in the chronic pancreatitis population ranging from one third (Bornman and Beckingham, 2001), to 30-50% (Mitchell et al., 2003), to 60-70% in patients with calcific pancreatitis (Tandon et al., 2002). In Malka et al's (2000) study, diabetes mellitus occurred a mean of 4.5 ± 5.9 years after the onset of the disease and the cumulative rate of appearance after 25 years was $83\% \pm 4\%$. This prospective cohort study of 453 patients with chronic pancreatitis supports Tandon et al's (2002) finding that the onset of pancreatic calcifications was the only clinical factor significantly associated with the risk of diabetes mellitus. The progressive destruction of the pancreas associated with chronic pancreatitis would then account for the cumulative increase in the incidence of diabetes mellitus. They claim that the earlier the onset of calcifications the greater the risk of diabetes mellitus and insulin requirement and, once they appeared, the risk increased by more than three-fold.

Endocrine pancreatic insufficiency can lead to the life-threatening complications of severe hypoglycaemia and chronic microangiopathic and macroangiopathic complications that occur as frequently in chronic pancreatitis patients with diabetes as in other diabetic patients (Gullo et al., 1990; Ziegler et al., 1994; Koizumi et al., 1998). Although international comparison is difficult due to the lack of standardisation mentioned earlier, a review of nationwide surveys in Japan highlighted that diabetes-related diseases such as renal failure, intractable pneumonia, diabetic coma and hypoglycaemia were the second most common cause of death (16) in a cohort of 127 (16.5%). In a long-term follow-up study of 715 patients with chronic

pancreatitis in Italy between 1971 and 1995 there were 176 deaths (Cavallini et al., 1998). Of these, 10 (5.6%) were as a direct result of hyper or hypoglycaemia and constituted the fifth most common cause of death. A further 15 (8.5%) died from cardiovascular disease but it is not possible from the data to ascertain if these patients also had diabetes.

The management of diabetes in chronic pancreatitis is generally similar to that of other diabetic patients with the exception that it usually requires insulin therapy, and ketoacidosis is rare (Tandon et al., 2002). It also becomes more difficult to manage in the presence of continued intake of alcohol and malabsorption or maldigestion. Furthermore, data from some studies suggest that chronic pancreatitis and diabetes mellitus are likely to be causally related to pancreatic cancer rather than being a consequence of it (Lowenfels et al., 1993; Malka et al., 2002)

2.7 Additional complications

2.7.1 Pancreatic cancer

The most sinister and devastating complication of chronic pancreatitis is pancreatic cancer. It carries with it a fatal prognosis due to late diagnosis and resistance to radiation and chemotherapy. Because of the high fatality rates, incidence rates of pancreatic cancer are almost equal to mortality rates (Michaud, 2004) and the average survival is 3-8 months (Adler, 2004). In the United States pancreatic cancer is the 4th leading cause of cancer death, while in Europe it is 6th. In Japan the major cause of death in patients with chronic pancreatitis is not the pancreatitis per se but other diseases, with cancer being the most common. In a cohort where there were 127 deaths, 63 were from malignancy, with pancreatic cancer being the most common (17 deaths) (Otsuki, 2003). Similarly in Italy, Cavallini et al (1998) reported pancreatic malignancy as the cause of death in 14 of the 176 deaths in their long-term follow up study of 715 people with chronic pancreatitis.

In patients with hereditary chronic pancreatitis, which is an autosomal dominant disease presenting in childhood and histologically identical to chronic pancreatitis of other aetiologies, there is a 53-fold increased risk for

the development of pancreatic cancer (Howes and Neoptolemos, 2002; Mitchell et al., 2003). In other forms of chronic pancreatitis the risk appears to be small with Mitchell et al (2003) claiming that traditional teaching holds that the disease is responsible for less than 5% of all pancreatic adenocarcinomas. However, they modify this statement with an observation that an improved understanding of the genetic basis of chronic pancreatitis and pancreatic cancer will probably result in an upward revision of this estimate. Tandon et al (2002) report that the risk has been estimated to be 16.5-fold higher than age-matched controls in a cohort study.

Malka et al (2002) revised this risk even higher in their prospective single centre medical-surgical cohort study of 373 patients with chronic pancreatitis. Sixty one patients died within the median follow-up period of 9.2 years (minimum 2 years) 4 of whom were patients who developed pancreatic adenocarcinoma. This was not considered a high incidence but the SIR (age and sex standardised incidence) was high at 26.7 and demonstrated a markedly increased risk in patients with chronic pancreatitis compared with age and sex matched controls. This increased risk was higher than that reported in previous case control (Bansal and Sonnenberg, 1995; Fernandez et al., 1995) and population based cohort studies (Ekbom et al., 1994; Karlson et al., 1997). Malka et al (2002) challenge the findings of previous studies by claiming that cohort studies are less prone to biases than case-control studies. In addition, they highlight concerns related to the diagnosis of chronic pancreatitis used in these previous studies and suggest that misdiagnosis and possible misclassification bias may have led to an underestimation of the relationship between chronic pancreatitis and pancreatic cancer. Howes and Neoptolemos (2002) concur and argue that the problems with methodological issues such as patient selection, ascertainment bias, small numbers and stringency of patient selection have led some authors to believe the risk of developing pancreatic cancer is confounded by other risk factors.

Such factors have been identified as the age of the patient and cigarette consumption. In respect of the former it is not clear whether this is a reflection of the patient's age per se or the duration of chronic pancreatitis. In

a study of 1552 patients with chronic pancreatitis a marked, independent increase in pancreatic cancer with age was found (Lowenfels et al., 1993). It was claimed that the relative risk was three times greater for a patient over the age of 60 compared with those who were younger. However, they also claim that the age at which pancreatic cancer develops in those with a history of pancreatitis is only a few years younger than those without a background history. Furthermore, even though there is an excess of males with chronic pancreatitis, sex does not appear to predict the subsequent development of cancer (Lowenfels and Maisonneuve, 2002).

Cigarette consumption is an important consideration in any study evaluating cancer risk particularly in chronic pancreatitis where a high proportion of patients smoke. This was evidenced by Cavallini et al (1998) in their study where the percentage of non-smokers at the onset of chronic pancreatitis was only 12% (n=86). The vast majority smoked >20 cigarettes a day (65%) and there was a close correlation between alcohol intake at onset of chronic pancreatitis and the number of cigarettes smoked. There was also a correlation between the years of alcohol abuse and years of smoking. In subsequent years, while there was a reduction in the intake of alcohol, the level of smoking appeared to remain more or less the same. This led Cavallini et al to propose that cigarette smoking has an influence on the clinical course of chronic pancreatitis as the incidence of pancreatic calcifications was found to be significantly greater in smokers than non-smokers. Other studies have also identified smoking as an independent variable in the development of pancreatic cancer (Lowenfels et al., 1993; Talamini et al., 1999; Lowenfels et al., 2001). Cavallini et al (1998) suggest, therefore, that medical practitioners should be advising their patients with chronic pancreatitis to not only stop drinking alcohol but also to stop smoking.

It appears to be evident that chronic pancreatitis has an effect on pancreatic cancer development (Cavestro et al., 2003). Some clinicians are suggesting that patients with established chronic pancreatitis undergo endoscopic ultrasound every year with fine-needle aspiration cytology or biopsy of suspicious masses in the pancreatic-duct wall. Those with dysplastic lesions or carcinoma in situ should be offered surgical resection as prophylaxis against

developing what is presently an almost 100% fatal cancer. The logistics of providing yearly ultrasound for every patient with chronic pancreatitis are immense but such screening might reduce the death toll from pancreatic adenocarcinoma (Mitchell et al., 2003)

2.7.2 Pseudocysts

According to Tandon et al (2002) pancreatic pseudocysts are the most common local complication of chronic pancreatitis with a reported incidence of between 10-40% (Steer et al., 1995; Tandon et al., 2002; Andrén-Sandberg and Dervenis, 2004; Cunha et al., 2004). They are 'encapsulated collections of pancreatic juice surrounded by a wall or capsule. They may regress spontaneously; persist with or without symptoms or result in complications' (Gouyon et al., 1997:821).

The difficulty in managing pseudocysts is assessing whether they will resolve spontaneously or will require intervention. According to Andren-Sandberg and Dervenis (2004) many reports on pseudocyst management do not differentiate between those that complicate acute disease and those that complicate chronic disease. As a result, evaluation of treatment options is difficult or impossible. This situation is complicated when no precise definition of the pseudocyst is offered in the study report and where the major cause is alcohol leading to selection bias that can threaten the reliability of the results (Andrén-Sandberg and Dervenis, 2004).

The risk for patients is associated with the development of complications of untreated pancreatic pseudocysts. These have been cited as pain, infection, fistula, rupture and intracystic haemorrhage (Andrén-Sandberg and Dervenis, 2004). Reports cited by Andren-Sandberg and Dervenis (2004) span a period of 30 years and are largely contradictory apart from an apparent consensus that cysts arising in those with chronic disease are less likely to resolve. Their management can include percutaneous drainage, surgical decompression by external or internal drainage and pancreatic resection (Fernandez-Cruz et al., 2002; Cunha et al., 2004), all of which require hospitalisation and further incapacitation.

2.8 Prognosis

About 50% of patients with chronic pancreatitis will undergo surgery at some stage for pain management or to manage their complications. In many cases, however, despite evidence of technical success no measurable improvement is seen in quality of life (Mitchell et al., 2003).

The prognosis of chronic pancreatitis is quite variable and tends to be affected by the presence of ongoing drinking in those with alcoholic pancreatitis. Continuous pain and continued drinking have a negative influence on quality of life with the latter also substantially influencing mortality. The mortality rate for those with alcoholic chronic pancreatitis is higher than for those with non-alcoholic disease. When compared with females, the prognosis for males is worse and can be explained by the aetiological differences (Otsuki, 2003).

Overall, chronic pancreatitis is associated with a mortality rate of up to 50% within 20-25 years. Approximately 15-20% of deaths are linked to complications of pancreatitis while most of the remaining deaths are due to trauma, malnutrition, infection or tobacco abuse (Steer et al., 1995). In a long-term follow-up study (n=816) by Cavallini et al (1998) the survival curve showed that 20 years after onset only 63% of patients remained alive. The main causes of death were malignancies associated with drinking alcohol or smoking, for example cancer of the mouth, oesophagus, stomach and lungs.

Non-malignant causes of death were cirrhosis of the liver and cardiovascular disease, which can be linked also with alcohol and smoking. It was noted, however, that in 23.9% (n=42) of the cases, the cause of death could not be established.

This overview of the impact of the pathological changes associated with chronic pancreatitis demonstrates the potentially devastating consequences for those given such a diagnosis. Intractable pain, malnutrition and/or maldigestion and diabetes mellitus could each, in their own right, be considered a chronic illness and each demands significant life adaptations. Add to these the uncertainty of the natural course of the disease, the ambiguity associated with treatment options and outcomes and the ultimately

poor prognosis and there is a significant cumulative effect in respect of patients' physical, psychological and social well-being. Furthermore, and as indicated earlier, approximately 70% of those with a diagnosis of chronic pancreatitis also have a history of alcohol abuse. In addition to learning to live with the diagnosis of chronic pancreatitis and all that entails, it is incumbent on them to abstain from alcohol. For those who have idiopathic chronic pancreatitis, there is a sense of helplessness associated with not knowing how or why they have developed this condition.

2.9 Health-related Quality of Life

The medical literature has, in recent years, begun to concern itself with health-related quality of life. Quality of life, according to Niv and Kreitler (2001) is a subjective, multi-dimensional, phenomenological, dynamic, evaluative, yet quantifiable construct. It is, essentially, a person's evaluation of his or her well-being and functioning in different life domains.

There appears to be several reasons why health-related quality of life is receiving attention. From a global perspective, Glise and Wiklund (2002) suggest that we live in a rapidly changing environment marked by social and economic instability. The emergence of new values has resulted, in some areas, in what they describe as the disablement of whole societies where the changes are likely to influence the working life, quality of life and disease patterns in society over time. Thus, they argue these aspects need to be considered when evaluating treatment of disease.

From a health consumer perspective patients are becoming more informed; they use the internet to seek information and educate themselves about their condition and in some instances may challenge proffered treatment options. Primarily, patients are demanding effective treatment for their symptoms. Patients, Glise and Wiklund (2002) contend, are concerned with their symptoms as indicators of disease regardless of the presence of organic or non-organic findings, whereas medical practitioners have focussed on histological and serological findings.

For many years the success of therapeutic modalities has only been seen from a medical point of view (Pezzilli and Fantini, 2005). However, there is a growing recognition of the importance of the subjective perceptions of patients in evaluating therapeutic interventions and the valuable insights to be gained into the burden of illness among diseased populations (Wehler et al., 2004; Fitzsimmons et al., 2005; Pezzilli and Fantini, 2005). Health-related quality of life is seen as a useful outcome measure in studies of chronic disease that is difficult to treat or have no cure, such as chronic pancreatitis. Evaluation of therapeutic interventions or treatment efficacy should be determined not only by its impact on symptoms but also on patient well-being and functioning.

2.10 Health-Related Quality of Life in Chronic Pancreatitis

In the chronic pancreatitis literature, there have been numerous calls for the development of a clinically robust tool for measuring health-related quality of life. The reasons for such a tool are largely similar to those cited above. However Talamini et al (2001) assert that such a tool is also necessary because of the plethora of therapeutic options available in the management of chronic pancreatitis. Clinical and social consequences of treatment options must be included in evaluations of efficacy where they could have enormous practical relevance. Furthermore, they maintain that in the future, evaluation of efficacy may be determined primarily on the basis of its impact on quality of life.

Studies that purport to evaluate quality of life of patients with chronic pancreatitis since 1990 fall into four main categories:

- Long-term follow-up studies that do not use Quality of Life Instruments but use measures such as morbidity, mortality, pancreatic function, pain and ability to work (Cavallini et al., 1998).
- Evaluation of specific interventions or comparison of interventions that do not use Quality of Life instruments but use parameters similar to those cited above (Stone and Chauvin, 1990; Markowitz et al., 1994; Büchler et al., 1995; Strum, 1995; Evans et al., 1997; McHale et al., 1997; Pap et al., 1998; Vickers et al., 1999; Proca et al., 2001;

Hutchins et al., 2002; Alexakis et al., 2003; Russell and Theis, 2003; Alexakis et al., 2004).

- Evaluation of specific interventions or comparison of interventions that use Quality of Life Instruments (Bloechle et al., 1995; Broome et al., 1996; Izbicki et al., 1998; Beger et al., 1999; De las Heras Castaño et al., 2000; Brand et al., 2000; Huang et al., 2000; Sohn et al., 2000; Howard et al., 2002; Witzigmann et al., 2002; Czako et al., 2003; Makarewicz et al., 2003; Olah et al., 2004).
- Evaluation of quality of life in chronic pancreatitis using Quality of Life Instruments (Wehler et al., 2003; Pezzilli et al., 2004; Wehler et al., 2004; Fitzsimmons et al., 2005; Pezzilli and Fantini, 2005; Pezzilli et al., 2005).

The studies cited above do not constitute a definitive list of all those that have been undertaken in relation to chronic pancreatitis. Studies prior to 1990 have been excluded as have those that do not make reference to outcome as the baseline parameter for quality of life. In a strict sense of the definition of quality of life offered above, the studies cited in the first two categories would not qualify. However, they are presented here to demonstrate the evolution from strict medical evaluation of the outcomes of chronic pancreatitis to a point where taking into account the perspective of the patient is seen as important.

2.10.1 Long-term follow-up studies using Quality of Life Indicators

Cavallini et al's (1998) long-term, follow-up study is reflective of the type of evaluation studies that were published, in the main, prior to 1990. They investigated epidemiological, clinical and radiological aspects of a cohort of 715 mixed medical and surgical patients with chronic pancreatitis in Italy between 1971 and 1995 with a median follow-up period of 10 years (range 1-25 years). This type of cohort study is valuable in terms of describing morbidity and mortality and a number of clinical characteristics including, type of chronic pancreatitis, age and sex distribution, smoking and alcohol trends, incidence of calcifications, pain, diabetes, steatorrhoea, pseudocysts and a range of co-morbidities. They serve to present a picture of chronic

pancreatitis and allow for comparisons with cohorts in other countries. However, quality of life from the perspective of the patient was not addressed nor were there any conclusions about the impact of the condition.

2.10.2 Evaluation/Comparison of interventions using Quality of Life Indicators

Studies that evaluated the efficacy of specific interventions or compared interventions were more prolific in the literature in the 1990s. This can be explained, in part, by the previously mentioned complex pathogenesis of the condition and the continued uncertainty about treatment and successful outcome. The studies are pre-dominantly related to evaluation or comparison of surgical interventions (Stone and Chauvin, 1990; Markowitz et al., 1994; Büchler et al., 1995; Evans et al., 1997; McHale et al., 1997; Vickers et al., 1999; Proca et al., 2001; Hutchins et al., 2002; Alexakis et al., 2003; Russell and Theis, 2003; Alexakis et al., 2004) and are mainly personal series or case control series by surgeons of their own patients. In addition, Strum (1995) examined the influence of alcohol abstinence on pain and outcome and Pap et al (1998) examined pain relief and functional recovery following endoscopic interventions. This latter study is reflective of the move towards alternatives to surgery in these patients.

Although these studies often produced a more realistic description of the life of the patients, the evaluations were largely medical and did not incorporate the perspective of the patients who endured the procedures with the resultant changes in their lives. Most of the studies addressed issues such as mortality and morbidity, length of hospital stay and pancreatic function with a minimum follow-up of six to twelve months. However, in respect of quality of life indicators, factors such as pain reduction or relief, weight gain, return to work or normal life style were also included. In studies where pre-and postoperative comparisons were made, determining statistical significance was possible in the areas of pain and weight gain. However, lifestyle factors were less easy to gauge and descriptions such as normal lifestyle, slightly restricted or severely restricted were commonly used. What is not clear is how these were determined. For example, in their randomised trial of two surgical procedures (n=48), Büchler et al (1995) claim the superiority of Duodenum

Preserving Head of Pancreas Resection over Pylorus-Preserving Whipple Resection is evident with regard to postoperative quality of life. However, it is not possible to ascertain how this claim was substantiated unless a correlation between reduced pain and quality of life is assumed or glucose metabolism and induction of diabetes mellitus, weight gain, and incidence of postoperative complications were interpreted as proxy quality of life measures.

2.10.3 Evaluation/Comparison of interventions using Quality of Life Instruments

In respect of their focus the third category of studies were similar to those in the second with a predominance of evaluations related to surgical interventions. However, there are some studies that are concerned with newer therapies such as endoscopic interventions (Brand et al., 2000), splanchnicectomies for pain relief (Howard et al., 2002; Makarewicz et al., 2003) and the impact of pancreatic enzyme replacement on quality of life (Czako et al., 2003). The essential difference with studies in the second category is the overt use of a recognised quality of life instrument. In Huang et al's (2000) and Czako et al's (2003) studies, the quality of life instrument was the only outcome measure used. However, in the remainder of the reports considerable emphasis was still placed on obtaining objective data such as morbidity, mortality and pancreatic function. Moreover, as all of the studies were evaluating some intervention, the quality of life instruments were used before and after for a follow-up period that ranged from a minimum of seven months (Brand et al., 2000) to 26 years (Beger et al., 1999). In addition, in Bloechle et al (1995) and Witzigmann et al's (2002) studies, two quality of life instruments were used. Whilst the stated purpose was to measure quality of life, the researchers also used these studies to assess and compare the reliability and validity of the chosen tools for their use with chronic pancreatitis patients.

Quality of life instruments that were used in these studies included the European Organisation for Research and Treatment of Cancer (EORTC QLQ-C30) (Aaronson et al., 1993), (Bloechle et al., 1995; Izbicki et al., 1998; Brand et al., 2000; Howard et al., 2002; Witzigmann et al., 2002; Czako et al., 2003), the Gastrointestinal Quality of Life Index (GIQLI), (Eypasch et al.,

1995), (Witzigmann et al., 2002; Olah et al., 2004), Spitzer's Quality of Life Index (Spitzer et al., 1981), (Bloechle et al., 1995), FACIT - Functional assessment of chronic illness therapy (Makarewicz et al., 2003), Medical Outcomes Short-Form 36 (Ware, 1997), (Broome et al., 1996), Karnofsky Performance Status Scale (Karnofsky et al., 1948), (Beger et al., 1999) and the City of Hope Medical Centre Quality of Life Survey (Ferrell et al., 1995a), (Huang et al., 2000; Sohn et al., 2000).

A criticism levelled against the choice of instruments for the above studies is their lack of specificity for assessing or measuring quality of life in patients with chronic pancreatitis (Fitzsimmons et al., 2005).

2.10.3.1 Karnofsky Performance Status Scale

In Beger et al's (1999) follow-up study of 504 patients who had duodenum-preserving pancreatic head resection between 1972 and 1996, 388 patients were evaluated four times between 1982 and 1998. They claim that fourteen years after surgery 69% of patients were professionally rehabilitated and in 72% the quality of life index was 90-100 and in 18% it was <80. To a certain extent these findings contradict other studies (Wehler et al., 2003; Wehler et al., 2004; Fitzsimmons et al., 2005; Pezzilli and Fantini, 2005; Pezzilli et al., 2005) that found a significantly impaired quality of life in patients with chronic pancreatitis. However, the quality of life measure used was the Karnofsky Performance Status Scale, which is a generic scale that measures functional impairment and makes assumptions about assistance required depending on the score. The difficulty with this scale is the interpretation of each of the statements. For example, a score of 80% is described as 'normal activity with effort: some signs or symptoms of disease'. It is classified in the same group as those who achieve 90% or 100% and is determined as 'able to carry on normal activity and to work; no special care needed'. Furthermore the correlation between functional status and quality of life is weak as the perception of quality of life is more than functional abilities (McMillan, 1996).

2.10.3.2 Spitzer Quality of Life Index

Another early tool used by Bloechle et al (1995) is the Spitzer Quality of Life Index that was developed for palliative care and validated within palliative care settings (Spitzer et al., 1981). It was designed as an objective quality of life index for use by physicians to enhance quality of life in patients with terminal cancer. The patient is interviewed by a healthcare professional, usually a physician, on topics such as activity level, social support and mental well being. These items are then rated on a three-point scale. In respect of patients with cancer this tool was found to have adequate internal consistency and inter-rater reliability. However, given its origins in palliative care, its construct validity for use with chronic pancreatitis patients must be questioned. Furthermore Bloechle et al (1995) were using the tool as a measure against which to judge their re-evaluation of the EORTC QLQ questionnaire for patients with chronic pancreatitis. Although it was a small study of twenty five patients who had duodenum-preserving resection of the head of the pancreas, with a maximum follow-up of 18 months at the time of reporting, the authors claim an improved quality of life for their patients and extol the validity and reliability for the EORTC QLQ for use with patients with chronic pancreatitis.

2.10.3.3 The Medical Outcomes SF-36

The Medical Outcomes SF-36 has been used widely in gastroenterology (Glise and Wiklund, 2002) and consists of a 36 item scale with domains of physical functioning, role limitation (physical), bodily pain, social functioning, role-limitation (emotional), mental health, vitality and general health perceptions. Although less sensitive to changes in specific symptoms, it is reliable in addressing the general impact of symptoms on a wide range of daily activities, mental health and functioning (Glise and Wiklund, 2002) and has been rigorously tested for its psychometric properties. Haywood et al (2005) found that of the generic instruments the SF-36 had a high level of reliability, validity and responsiveness across a range of settings. However, whether it has the necessary responsiveness to change for comparing specific interventions or treatment pathways is speculative even though it has been

suggested that a change or difference in five score units may be clinically relevant in the SF-36 (Glise and Wiklund, 2002)

Broome et al (1996) used the SF-36 in a retrospective study evaluating quality of life following pancreatic debridement for necrosis. Twenty two patients of a possible 40 were recruited to the study. The SF-36 was administered by telephone at an average of 51 months post-debridement. The tool was also administered to two other groups, chronic pancreatitis patients who were medically managed (n=89) and a surgical group (n=37) who had surgery for ductal abnormalities. The findings of this study are difficult to evaluate due to a number of issues. The use of the SF-36 instrument is questionable in samples where there is the possibility that it has insufficient power to detect quality of life differences between similar groups as was the case in this study. There was also the possibility of a type 2 error as no statistical difference was noted between the groups and the study sample size was small. Furthermore, the number of patients ultimately recruited to the medically and surgically managed groups was not outlined. An age match control was used as a reference population but no statistical manipulation was undertaken with the study numbers. Although an important early study in terms of highlighting the need for subjective quality of life assessments in patients with chronic pancreatitis, the study itself offered little in terms of conclusions about the reality of the patients' experiences.

2.10.3.4 City of Hope Quality of Life (COH) Tool

The City of Hope Quality of Life Tool (COH) originally developed for assessing quality of life in cancer patients was modified and used in two studies that included people with chronic pancreatitis (Huang et al., 2000; Sohn et al., 2000). In developing this tool, Ferrell et al (1995b) revised a previous instrument and then conducted a further study to evaluate its psychometrics including measures of reliability and validity with cancer survivors (Ferrell et al., 1995a). In this group of patients, the instrument supported construct validity, test-retest coefficients were satisfactory and internal consistency was high. The extent to which the instrument measured the concept of quality of life was evaluated using measures of validity that included content, predictive,

concurrent, construct and discriminate validity. The findings indicated that the instrument adequately measured quality of life in cancer survivors.

Huang et al's justification for its use in their study was that 56% of their patients had malignant pathologies, the remainder having benign pathologies such as chronic pancreatitis. In this retrospective study of patients surviving pancreaticoduodenectomy between 1981 and 1997, questionnaires were sent to 323 patients (return of 192). They also sent the questionnaire to 100 patients (return of 37) who had laparoscopic cholecystectomy as a comparable control group and 100 healthy controls (return of 31). The patients in the surgical groups had to be at least six months post surgery. For patients with chronic pancreatitis the possible short interval between the intervention and the evaluation could be confounding as expectations or hope of improvement influence health-related quality of life. Values are often super-normal in the periods immediately post-treatment with a levelling off after some months (Glise and Wiklund, 2002). A supplement to the questionnaire was sent to both surgical groups inquiring about functional outcomes but the authors have not outlined how these items were constructed. Moreover, validity and reliability measures for the use of the instrument with patients with benign pathologies appear to have been overlooked. As McMillan (1996) claims, instruments should be developed within the settings in which they will be used. Despite these limitations and the caution that must be exercised regarding the findings, the study indicated that quality of life for patients with chronic pancreatitis was lower than the malignant pathology and laparoscopic cholecystectomy groups in all domains (physical, psychological and social). However, the reasons for this could only be speculated upon.

Sohn et al's (2000) 17-year review (1980-1996) of 263 operations in 255 patients with chronic pancreatitis also used a modification of Ferrel et al's (1995a) instrument. They addressed content and construct validity for patients with chronic pancreatitis by undertaking the modification in conjunction with surgical staff and a small sample of chronic pancreatitis patients, the number of which was not specified. Test-retest reliability was confirmed by redistribution of duplicate questionnaires to a sub-set of patients at a second point in time. The questionnaire was sent to 227 patients alive at

the time of the survey and the response rate was 47% (106). Patients were asked to respond to multiple aspects of quality of life before and after surgery where they acted as their own control and responses were compared using a paired *t*-test. However, it appears that assessment of pre-operative quality of life was retrospective, a factor that could have been mediated by the accuracy of the perception of events that could have occurred some time previously. Nonetheless, Sohn et al argued that surgery resulted in a highly significant improvement in all quality of life measures.

2.10.3.5 Gastrointestinal Quality of Life Index (GIQLI)

Although not specific to chronic pancreatitis the Gastrointestinal Quality of Life Index (GIQLI) addresses pain, bloating, strength endurance, sadness, nervousness, dysphagia and diarrhoea, which allows it to be used in a range of gastrointestinal conditions. Witzigmann et al (2002) used the GIQLI in their study as it had been used on one previous occasion with patients with chronic pancreatitis (McLeod et al., 1995). It must be assumed therefore, that their purpose in selecting it was to attempt to establish its reliability and validity for use with patients with chronic pancreatitis. It was used as a comparison with the EORTC QLQ C-30 instrument whose validity and reliability, they claim, had already been established with chronic pancreatitis patients. The purpose of this prospective trial was to compare classical Whipple Procedure (PD) with Duodenum-preserving Pancreatic Head Resection (DPPHR). Sixty-five patients were recruited to the study with the sample split according to their type of surgery (35 and 30 respectively). The quality of life questionnaires were prospectively assessed at three points during the study; pre-operatively in the week prior to surgery, 9-12 months and 18-24 months after surgery. Their conclusion was that the EORTC QLQ – C30 was superior in measuring quality of life than the GIQLI. GIQLI provided a good internal consistency but the content validity was deemed to be low for this group of patients. Furthermore they claim that its criteria-based validity was reduced because the correlation with parallel scales in the EORTC QLQ-C30 was low. This conclusion was based on their contention that the EORTC QLQ C-30 had excellent validity in measuring overall quality of life.

Both instruments demonstrated a markedly reduced quality of life pre-operatively with improvements demonstrated in both groups postoperatively particularly in the 18-24 month assessment. In keeping with the primary purpose of the study, differences in quality of life between the PD and DPPHR groups were focussed upon in the evaluation. These achieved statistical significance in all domains of the EORTC QLQ C-30 instrument whilst it was evident only in the symptoms and physical status domains of the GIQLI. It appears then, that the issue of content validity may be associated with the emotional and social functioning and medical treatment domains. However the limited discussion in the report precludes any conclusions. Furthermore, the nature of prospective studies means that conclusions about the long-term impact on quality of life in a chronic condition such as chronic pancreatitis are tentative at best.

Olah et al's (2004) study that also used the GIQLI appears to support this contention. Their study, which focussed on the long-term follow-up (mean of 86 months) results of surgery for chronic pancreatitis on 87 patients between 1990 and 1994 appear to suggest that only 34% of patients investigated achieved 'good results'. The rate of disability was found to be 51% and the researchers cautioned that short-term, follow-up results may be deceptive and the real outcome can only be determined five years following surgery.

2.10.3.6 Functional Assessment of Chronic Illness Therapy Instrument (FACIT)

Makarewicz et al (2003) used the Functional Assessment of Chronic Illness Therapy (FACIT) instrument, in a small-scale prospective study of 32 patients who were treated with Videothoroscopic Splanchnicectomy (VSPL) for intractable pain. The FACIT instrument is an expansion of the original core questionnaire called the Functional Assessment of Cancer Therapy General (FACT-G). The FACIT tool (Cella, 2006) has considerable potential as a generic tool for use with groups or populations with chronic conditions. It allows comparisons across these groups but with the continued development of sub-types will also allow for evaluation across international populations and cultures with the same condition. Its limitation in clinical trials is that it is not applicable for comparisons with healthy cohorts. Internal consistency and

test-retest reliability of the FACIT instruments have been shown to be good. Content/face validity was built in the instrument by relying on oncologists and patients to shape the development and content of the forms. Construct validity is satisfactory and the instruments were shown to be able to detect changes over time. However, given the manner of scoring, non-responses to items on the questionnaire pose problems and may impact on the clinical relevance of the score. The website specifies, however, that work on this issue and that of clinical significance is continuing (Functional Assessment of Chronic Illness Therapy Organisation, 2006).

Makarewicz et al (2003) used a sub-type developed for pancreatic and hepatobiliary diseases (FACT-Pa – Version 4) covering aspects of emotional, social, physical and functional well-being plus issues specific for pancreatic diseases. They state that the instrument was normalised to American conditions but the manner in which this was achieved was not delineated. The control group in their study were patients with chronic pancreatitis who were not treated with VSPL. Patients in the study completed the FACIT questionnaire pre-intervention and again at 1, 3, 6, 9 and 12 months post intervention. The study authors acknowledge the limitations of its short-term follow-up and therefore the preliminary nature of its findings. Although the sensitivity of the instrument in measuring quality of life was not specifically discussed, the findings appear to corroborate that pain alleviation does not necessarily result in sustained improvements in all domains of quality of life. For example, improvement in emotional status and everyday functioning was most significant whereas physical status and social well-being did not show the same benefit. This would seem logical following an intervention that should not affect ultimate physical status as chronic pancreatitis progresses. In addition, social well-being has a psychosocial dimension that would not be affected by an intervention such as VSPL. Although this study appeared to support the use of the FACIT tool with chronic pancreatitis patients, this would need to be verified with further work.

2.10.3.7 European Organisation for Research and Treatment of Cancer Instrument (EORTC QLQ – C30)

The instrument most commonly used in this category of studies was the EORTC QLQ – C30, which is a core module developed to assess quality of life issues for all cancer patients. (Bloechle et al., 1995; Izbicki et al., 1998; Brand et al., 2000; Howard et al., 2002; Witzigmann et al., 2002; Czako et al., 2003). It is a 30 item instrument that includes physical function, role function, cognitive function, emotional function, social function, symptoms and financial impact. In terms of its use in cancer the core module is supplemented by disease specific modules. Testing of reliability and validity has taken place with large groups of patients with a wide variety of cancers and with non cancer groups such as HIV and chronic noncancer pain (European Organisation for Research and Treatment of Cancer, 2006). The internal consistency of the tool is seen to be good (Cronbach's alpha >70). Content/face validity is deemed acceptable, while discriminative validity is stronger for role and social function scales and global items but weaker for cognitive and emotional function. Convergent validity showed inter-instrument agreement to be excellent for the global questions and the emotional and role function sub-scales and fair to good for the social function and cognitive sub-scales. QLQ C-30 has been shown to be able to detect changes over time and is considered appropriate for use in clinical trials. The instrument has been used and endorsed as a suitable measure in chronic pancreatitis studies. It has been adapted to include pancreas specific questions although the process by which these questions were developed has not been described (Bloechle et al., 1995; Izbicki et al., 1998; Howard et al., 2002; Czako et al., 2003). According to Fitzsimmons et al (2005) they appear to be based on clinical opinion and have not been developed according to the published guidelines for Quality of Life Module development. Nonetheless, the reports appear to indicate satisfactory validity and reliability.

Bloechle et al (1995) in the oldest of these studies attempted to establish the validity and reliability of the EORTC QLQ C-30 for use with patients with chronic pancreatitis. As previously discussed, this study also used the Spitzer's Quality of Life index. They concluded that the EORTC QLQ C-30 was a useful tool for evaluation even though their sample size was only 25

patients. Nonetheless, on the basis of their assertions, subsequent studies claimed the instrument was valid and reliable (Izbicki et al., 1998; Howard et al., 2002; Witzigmann et al., 2002).

Izbicki et al's (1998) prospective randomised trial compared extended drainage versus resection in surgery for chronic pancreatitis commencing in 1995. Of the 64 eligible patients, 61 were recruited and randomly allocated to either the resection (n=30) or extended drainage (n=31) groups. The authors claim there was no significant difference between the groups with regard to age, sex and distribution of pathological findings. The findings suggest that in respect of quality of life, both groups achieved statistically significant improvement in quality of life in function and symptom scales, as compared to the pre-operative values. They also claim that the improvement was 200% in the extended drainage group and 100% in the resection group, based on the global quality of life score. Although the quality of life results were presented in tabular form there was little discussion of these in the text and some of the claims are difficult to interpret. Additionally, as this is a prospective study with a limited range of follow-up (12 - 24 months) some caution must be exercised in respect of long-term outcome. Furthermore there were no statements about the applicability of the instruments used or its adaptation for these groups of patients.

Brand et al (2000), Howard et al (2002) and Czako et al (2003) also undertook prospective studies but they focussed on evaluating the impact of one intervention. Brand et al (2000) studied 48 patients with chronic calcifying pancreatitis who were recruited for Extracorporeal Shockwave Lithotripsy (ESWL) between October 1996 and October 1997. Ten of these patients were subsequently lost to follow-up. Quality of life assessments were undertaken before treatment and six months after but the only reference to the quality of life findings was to assert that the global quality of life improved in 68% of patients. However, this was difficult to align with the tabulated symptom and function scales where statistically significant improvement was very limited and was completely absent in the functional scales. As with Izbicki's et al (1998) study, there was no textual discussion of the quality of life findings or the applicability of the instrument used. However, the

researchers did caution that the large number of outcome criteria and the small sample size precluded confirmation of the findings.

Howard et al (2002) prospectively evaluated health-related quality of life in 55 patients with small-duct chronic pancreatitis between 1997 and 2001, with a median follow-up of 32 months following bilateral thoracoscopic splanchnicectomy for intractable pain. The patients in the study were subsequently split into those who had prior endoscopic interventions (n=38) and those who did not (n=17). The EORTC QLQ instrument that had been adapted previously by Bloechle et al (1995) was used and administered on the first pre-operative clinic visit and at 3, 6, 12, 24 and 36 months postoperatively. Findings from the quality of life data were reported according to the groups. Therefore, it was not possible to ascertain if an overall improvement had been achieved. Differences between the groups were detailed and improvement in global quality of life, physical, role, cognitive and social functioning was statistically significant for the 'no previous intervention' group. Conversely the 'prior intervention group' had returned, for the most part, to pre-operative levels of pain and showed little or no improvement in quality of life by twelve months.

In Czako et al's (2003) prospective, multi-centre, follow-up study the EORTC QLQ C-30 was modified with the addition of two questions about steatorrhoea and used for assessing quality of life in patients with chronic pancreatitis before and after pancreatic enzyme replacement therapy. Two groups of patients were evaluated one of which comprised newly diagnosed patients who had never been treated (n=31) and the other patients with an average of 3.4 years post-diagnosis whose pancreatic replacement treatment had been deemed insufficient (n=39). Following a course of tailored replacement therapy, it was found that the global quality of life in both groups was significantly improved and correlated with an improvement in body weight and decrease in defaecation number. As with other studies, the post intervention assessment time was short and therefore the findings must be viewed with caution. However, what was of interest was the apparent ability of the modified instrument to distinguish between results in the symptom and function scales between groups with the same condition. For example, the

patients in Group 1 demonstrated a significantly reduced level of hope and confidence compared to Group 2 but only those in Group 1 had significant improvement in cognitive functioning.

Although it could be said that the studies in this series used health-related quality of life as a secondary outcome after symptom relief, they are also reflective of the growing awareness of the need for subjective evaluation of quality of life from the patients' perspective. In some of the studies the drive to develop an instrument that is reliable and valid for use in clinical trials of chronic pancreatitis is also evident. All of the instruments used, apart from the Karnofsky Performance Scale, appear to reflect the subjective, multi-dimensional nature of quality of life and are able to detect a difference between quality of life before and after the intervention being evaluated. Nevertheless, there were issues of content validity for those instruments that were developed for other disease groups, for example, cancer patients. Moreover, the nature of a disease and its associated disability can influence several of the variables in a quality of life measure. As Glise and Wiklund (2002) suggest, some conditions can result in socioeconomic deterioration and emotional crises with attendant loss of job, friends and partners whilst in others support from friends, family and colleagues can actually increase the positive effects in these aspects. Thus, using instruments such as the Spitzer Quality of Life Index and the EORTC QLQ C-30 without modifications or explication of those modifications in patients with chronic pancreatitis has an impact on their ability to measure what they are supposed to measure.

Pezzilli and Fantini (2005) outline that for the most part these are studies by surgeons and endoscopists evaluating their own interventions with their own patients. Whilst they may be deemed necessary in a condition such as chronic pancreatitis where treatment is notoriously difficult and complex to manage, they are unable to present an overall view of quality of life per se for these patients. All of the studies suggested a poor quality of life prior to treatment but few alluded to the significance of this as a global issue. There was no reference to the impact or severity of the treatment regime itself and the short follow-up time in many of the studies could have impacted on the results. Glise and Wiklund (2002) report that a patient's expectations or hope

of improvement has profound effects on health-related quality of life where in the immediate post treatment phase results can be super-normal but return to normal after a few months.

From a methodological perspective, several of the studies had poor response rates (Huang et al., 2000), sample sizes were small (Bloechle et al., 1995; Broome et al., 1996; Izbicki et al., 1998; Brand et al., 2000; Howard et al., 2002; Witzigmann et al., 2002; Makarewicz et al., 2003; Czako et al., 2003) and information regarding patients lost to follow-up was limited apart from mortality rates. Therefore, there is a bias introduced by a failure to capture health-related quality of life measures in patients leaving the studies (Glise and Wiklund, 2002).

Overall there is a perception in these studies that interventions are a panacea for quality of life issues with patients with chronic pancreatitis. Yet most of the studies, despite the positive outcomes described, demonstrate that a reduced quality of life is a feature of living with chronic pancreatitis.

2.10.4 Evaluation of Quality of Life using Quality of Life Instruments

The final category of studies acknowledge the limitations of previous work and have attempted to evaluate quality of life in chronic pancreatitis using Quality of Life Instruments (Wehler et al., 2003; Pezzilli et al., 2004; Wehler et al., 2004; Fitzsimmons et al., 2005; Pezzilli and Fantini, 2005; Pezzilli et al., 2005).

Wehler et al (2003; 2004) report on a study that recruited 265 patients between January and December 2000 from a gastroenterology department in Bavaria. Patients had chronic pancreatitis of varying severity. Clinical and demographic data obtained at an assessment interview and from patient recall included previous and current alcohol use, smoking habits, frequency of pain, analgesic use and time absent from work in the preceding 12 months. Using the German language version of the Medical Outcomes SF-36 instrument, data were obtained at the patient's home by interview (32%) or by telephone (68%). The choice of a generic instrument was related to the

non-availability of a disease specific tool. From the available generic tools, the SF-36 was chosen because it has excellent reliability and validity when employed with diverse medical conditions and there was a validated German version. The SF-36 values of patients with chronic pancreatitis were compared with matched population norms computed from the German Federal Health Survey.

The results of the study demonstrated that, regardless of treatment regime, patients with chronic pancreatitis reported considerably lower scores in all SF-36 scales compared with the age- and gender-adjusted German general population with the most pronounced impairments in the role-limitations physical, role-limitations emotional and general health perception. If the 5-10 point difference in Short Form-36 scale is deemed to be clinically important then the German sample had clinically important deterioration in all health-related quality of life domains except social functioning.

Severity of pain and decreasing body mass index were significantly associated with a decline in health-related quality of life. Patients who had continued alcohol abuse scored lower in the vitality domain and those who were unemployed or retired early were the most severely disabled in the sample with lower scores than other patients. Multiple regression analyses with the SF-36 physical component as a dependent variable indicated that pain index, body mass index, chronic pancreatic diarrhoea, unemployment, early retirement and age significantly and independently accounted for 33.8% of the variance in the final model and were closely associated with poor response in most domains and both comprehensive indices of health-related quality of life (Wehler et al., 2004). Additionally, the most severely disabled group were younger than other patients, had a longer duration of chronic pancreatitis and were more likely to have an alcohol aetiology and continuing alcohol abuse. Wehler et al (2004) also found that one in four of the patients in their sample met the criterion for diagnosis of clinical depression indicated by a summary score of ≤ 42 in the SF-36 mental component. This differs from a study by Petrin et al (1995) who used the Zung Self-rating Depression Scale in a group of 60 patients with chronic pancreatitis who had undergone various surgical treatments. After a mean follow-up of 8 years, they found no statistical

evidence to support the contention that these patients suffered from clinical depression. However Wehler et al (2004) suggest this may be due to the low level of pain reported by their patients.

In respect of the impact of co-morbidities like diabetes, they found that although a reduction in health-related quality of life was evident, it did not reach statistical significance. This lack of sensitivity, they claim, could be explained by a floor-effect of the generic SF-36 scale where their patients were already at the low end of most of the scales.

Although Wehler et al (2004) felt their patients may reflect more disease severity coming from a tertiary referral centre than patients from a primary care or community gastroenterology practice setting, Pezzilli and Fantini's (2005) and Pezzilli et al's (2004; 2005) study reported similar findings. The study took place in Italy with 190 patients admitted from January 2003 to June 2003. One hundred and seventy one patients completed the self-administered SF-36 scale with nineteen declining to take part. Their rationale for choice of SF-36 scale was similar to that of the German study and an Italian version of the scale was available. The results confirmed those of the German study with the exception of gender variations in the domains of general health, vitality and social functioning where females scored lower than their male counterparts. This is explained by the researchers as a poorer acceptance of the disease by females in the study and supported by the lower scores of females in the mental component summaries. They also identified that male patients who were smokers, those with a long history of alcohol consumption, those with long duration of the disease and those who were pain free were less available to take part in the study.

These two studies represent a significant move towards health-related quality of life as an important factor in the assessment of the burden of disease amongst those with chronic pancreatitis. This view is supported by the findings that pancreatic morphology changes were not significantly associated with any domain of health-related quality of life and did not coincide with patients' subjective experiences. Additionally, both studies highlight that neither the type of pancreatic surgery or endoscopic therapy were able to

modify substantially the physical and mental domains explored by the SF-36. This contradicts the findings of many of the intervention studies previously discussed but could be explained by the highly selective nature of their patients and the short interval time between intervention and evaluation (Pezzilli and Fantini, 2005). The findings also suggest that studies of the global impact of chronic pancreatitis on quality of life can raise physician awareness of patients' physical and mental problems and may even identify those who require more intense support including psychological counselling.

However Fitzsimmons et al (2005) argue that generic instruments such as the SF-36 are limited in terms of their sensitivity to measure clinical responsiveness. Although this is a questionable criticism given that a difference in score of 5-10 is deemed clinically important, there is a question about whether or not the scale contains enough specificity about issues that are important to patients with chronic pancreatitis. To some extent, this argument could be supported by the floor effect seen in the German and Italian studies where it was not possible to identify and/or isolate the effects of co-morbidities in chronic pancreatitis. Moreover, in the German study the economic status and the environmental setting could not be adjusted for in the statistical analysis (Wehler et al., 2004). Nonetheless, whether this latter factor could be accounted for in a disease-specific tool is speculative.

According to Glise and Wiklund (2002) specific diseases are best followed by disease-specific instruments, which are regarded as being more useful clinically as they are more sensitive to the effects of interventions and time-trends in a specific condition. However, due to their specificity they do not allow comparisons with other conditions. A disease-specific instrument for chronic pancreatitis does not exist but Fitzsimmons et al (2005) conducted a study to evaluate the applicability of the EORTC QLQ C-30 and the QLQ-PAN26 sub-type (EORTC pancreatic quality of life module) developed for pancreatic cancer in patients with chronic pancreatitis. They argue that the clinical features of pancreatic cancer and chronic pancreatitis are similar and hypothesise that the EORTC QLQ C-30 with the QLQ-PAN26 together would cover the most important and relevant aspects of quality of life for chronic pancreatitis.

The development of the EORTC QLQ – PAN26 involved a patient-centred approach to instrument development and validation where quality of life issues were generated from their own illness and treatment experiences. The instrument has been translated into 16 languages and its psychometric properties are being evaluated following use in several multi-centre pancreatic cancer trials (Fitzsimmons et al., 2005).

In assessing the applicability of the instrument for chronic pancreatitis patients, a three stage approach was taken. Firstly a literature review concerning quality of life in chronic pancreatitis was undertaken followed by a descriptive analysis of the papers. Secondly, patients with confirmed chronic pancreatitis were identified in follow-up clinics and the questionnaires were completed by 66 patients in four centres in Germany (n=25), Italy (n=12), South Africa (n=16) and the United Kingdom (n=13). The questionnaires were completed in the presence of an interviewer where each patient was asked to discuss in a think-aloud format their perception of the relevance of the items therein. On completion of the questionnaires they were asked to identify any significant omissions and check for irrelevant items. There were 4% missing responses (patient declined to answer), which related to the ability to carry out self-care activities in the QLQ-C30 and the sexual functioning questions of the QLQ-PAN26. No possible explanations for this occurrence were explored in the subsequent discussion. Several tests of psychometric evaluation were subsequently undertaken. The internal consistency for the majority of the scales was endorsed and there was evidence of construct validity. Discriminant validity also appeared to be good. In the final stage the results of the previous stages were presented to the project group where the original tool had two items added related to alcohol consumption and the burden of abstention. This resulted in the creation of the QLQ – PAN28 (CP) for future evaluation and preliminary clinical use.

The findings of this study largely reflect those of Wehler et al and Pezzilli et al but issues related to fear of future health and difficulty in sleeping appear to support Fitzsimmons et al's (2005) contention that patients with chronic pancreatitis face a wider range of quality of life issues. Moreover, the

identification of guilt about continued alcohol use or the burden of abstinence seems to exemplify matters that are of particular concern and support the development of a disease specific instrument.

However, in keeping with all the studies discussed previously, the conclusion of the researchers appears to be in producing a tool that allows comparison of therapeutic interventions. This suggests that the primary goals for patients with chronic pancreatitis are intervention-based thus perpetuating the notion that they are a panacea for quality of life issues.

2.11 Summary

Overall, what appears to be clear from the review of the studies is that the use of multiple tools precludes comparison and responsiveness and clinical significance is difficult to measure. Moreover, the measurement of quality of life in many of these studies had an end-point, which was simply to attempt to demonstrate the efficacy of the intervention. It appears that the important factor was demonstration of an improvement of quality of life regardless of whether it would still be considered poor in comparison to a healthy control group.

There were also issues of validity and reliability with some of the chosen tools. This would seem to support the need to develop a widely accepted reliable and valid tool for use with patients with chronic pancreatitis. The benefits of a generic tool like the SF-36 scale include its excellent reliability and validity, the ability to explicate the wider impact on health-related quality of life and facilitate studies with different populations of chronic pancreatitis patients. It also has the potential to identify the burden of the disease on those experiencing chronic pancreatitis as well as enabling comparison with patients with other chronic conditions. The other instrument that has similar potential for comparison is the FACIT tool but as previously mentioned it would not be useful in trials where a comparison with healthy cohorts was required.

In respect of disease-specific instruments for use with patients with chronic pancreatitis the EORTC QLQ C-30 combined with the QLQ PAN28 is the only one available and as yet it has to be further tested and validated. Its use for

comparison with cohorts of chronic pancreatitis patients is a strength and its potential in terms of determining clinical responsiveness could be significant.

There is, however, an argument for the inductive development of a quality of life instrument for patients with chronic pancreatitis. Fitzsimmons et al (2005) acknowledge that, ideally, question generation should be undertaken by interviews with patients. However, in their study they claim that because of the similarity with symptoms and treatment options in pancreatic cancer and chronic pancreatitis the question generation stage could be bypassed. Although they did include patients in their evaluation of the QLQ PAN-26 and asked for omissions, the presentation of pre-selected items may have impeded identification of other issues apart from the burden of abstinence from alcohol and continued alcohol use, which is not surprising in chronic pancreatitis given its main aetiology.

2.12 Conclusion

Overall, all of the studies cited in this review endorse the view that patients with chronic pancreatitis have a significantly impaired health-related quality of life. Yet with the exception of Wehler et al's (2003; 2004) and Pezzilli et al's (2004; 2005) studies, that allude to the importance of identifying those who may have differing and significant additional needs such as psychological support, recommendations and implications from the studies cited here continue to focus on the medical and surgical management of the condition. There is little mention of the need to involve other members of the interprofessional health-care team or the possibility of developing strategies in the community to maximise patients' self-care abilities. To some extent, this focus is not surprising given that all the studies were located in the medical literature and issues of quality of life from this perspective concentrate on health- and illness-related variables (Anderson and Burckhardt, 1999). Currently, studies of quality of life in chronic pancreatitis are limited by this perspective and work such as that undertaken in this study could broaden the outlook by explicating the subjective elements of this holistic and multidimensional concept.

No study could be located that examined any aspect of quality of life amongst patients with chronic pancreatitis living in Ireland. Yet supporting people living with chronic conditions is a key government target. In Quality and Fairness – a Health Strategy for you (Department of Health and Children, 2001b) the need was identified for chronic disease management protocols to promote integrated care planning and support self-management. However, if the chronic disease group remains hidden and silent their needs cannot be met. Therefore, exploration, explication and understanding of living with chronic pancreatitis is important because of the physical, psychological and social burdens placed on individuals diagnosed with the condition. This group may have needs and concerns that are common to other chronic illnesses but it is the manner in which these are particularised that necessitates explication. Furthermore, the impact and burden on immediate or close family and informal carers is not known. Although people with chronic pancreatitis can spend significant periods of time in the acute hospital setting, in keeping with many chronic illnesses, much of the management is undertaken and maintained by the individual and their family in the community. There is therefore a need to identify the collective burden borne by patients and their relatives so that strategies can be developed and implemented to maximise the potential for self-management of this condition.

CHAPTER 3 – PHILOSOPHICAL FRAMEWORK

3.1 Introduction

As indicated in Chapter 1, this study is one that focuses essentially on interpreting and understanding what it means to live with chronic pancreatitis. Thus, hermeneutics, the science and art of interpretation would appear logically to provide an appropriate philosophical underpinning. However, as Fleming et al (2003) state, there is no one hermeneutic rather it is a disparate field with diverse views among its proponents on ontological and epistemological questions. Therefore, this chapter begins with a short exploration of the evolution of modern hermeneutics in order to situate its significant ontological turn in the 20th century. The work of early key philosophers in modern hermeneutics such as Schleiermacher and Dilthey are mentioned briefly as they represent notable turning points in the hermeneutic journey but also symbolise important approaches to the problems of interpretation. The hermeneutics of Martin Heidegger is included because, as Packer (1985) argues, it is neither possible to understand or critique modern hermeneutics without some familiarity with his work. Moreover, it provides an important backdrop for understanding the philosophical hermeneutics of Hans-Georg Gadamer (1976; 2004), which ultimately informed the study. A critical exposition of the central concepts of Gadamer's hermeneutic follows, with particular emphasis on those that have relevance for the subsequent operationalisation of the study.

Ultimately, this chapter constitutes an explication of my interpretation and emergent understanding of hermeneutics and the philosophy of Gadamer in relation to this study and I would contend it is itself hermeneutic. It began from my own standing as a person but also a nurse and researcher, whose world view incorporates beliefs about the value of qualitative research as a means of accessing patients' experiences in order to understand better and, in so doing, practice better. Yet, reading and accessing materials and texts about hermeneutics identified a world that was foreign to me in terms of its discourse, language, theories and concepts. Possibilities for understanding its complexities were further obscured as much of the seminal work in modern

hermeneutics is written in German, which renders it inaccessible to me in its original form. Therefore, my interpretation is another layer of interpretation upon that which has already been interpreted by virtue of being translated into English. Moreover, the published expositions, commentaries and critiques of the work of hermeneutic philosophers are also interpretations undertaken from the particular world view and frame of reference of the various authors. In addition, disagreements exist among philosophic commentators as to the accuracy of some translations or interpretations, which creates a tension for the novice student of hermeneutics who, in attempting to understand, may ultimately misunderstand. Consequently, whilst I have been as rigorous as I can be in my efforts, I acknowledge that not only is my interpretation and understanding mediated by that which is available to me but also that it is contingent on the limits of my own ability to comprehend the meaning of these texts at this time.

3.2 Hermeneutics

Hermeneutics is derived from the Greek verb *'herméneuein'*, which is generally translated to mean 'to interpret' 'to explicate', 'to translate' and the noun *'hermeneia'* meaning 'interpretation' (Palmer, 1969; Moules, 2002; Lawn, 2006). The term is also associated with Hermes, who interpreted the wishes of the gods and made them known to humans (Moules, 2002). Since its ancient origins, the oldest and most widespread understanding of hermeneutics has been associated with rules, methods or theory governing interpretation, illumination and exposition of biblical literature (Palmer, 1969).

Although the focus of this discourse is on the birth and evolution of modern hermeneutics since Schleiermacher, it is important to note that the advent of rationalism had a significant impact on the subsequent course of hermeneutics. Rationalism, which in its broadest sense appeals to reason as a source of knowledge or justification, and the publication of Descartes' *Discourse on the Method* in 1637 had a significant impact on philosophical thought and the foundations and conceptions of truth (Lawn, 2006). Primarily, Descartes sought to base the foundations of philosophical thought on reason alone and rejected any appeal to tradition or textual authority such as that of ancient Greek philosophy, classical literature, scripture or the Bible, which

until that point had been the focus of scholastic philosophy (Lawn, 2006). Thus, science became independent of the previous influence of metaphysics through explication of their epistemological foundations and development of their methodology (Rickman, 1976). In an effort to align themselves with the new model of knowledge, biblical interpreters argued that scripture, particularly the New Testament, contained intended, rational, moral truths and it was simply a matter of entering the texts in such a way as to reveal them. As a result, subsequent interpretive endeavour focussed on developing a means of aligning scriptural truths with the 'truths of reason' (Palmer, 1969:39). By using the tools of natural reason and developing historical understanding, it was thought the spirit or intention of the texts would be revealed in a manner that would be acceptable to the reasoning of the Enlightenment (Palmer, 1969). Consequently, methods of biblical hermeneutics became synonymous with classical philology or secular theory of interpretation with the Bible being only one of a possible number of objects for study (Palmer, 1969).

3.3 Schleiermacher

There is a view that until the advent of the philosopher Schleiermacher hermeneutics did not exist as a general field but consisted of several forms of specific hermeneutics (Palmer, 1969; Grondin, 2003a). Schleiermacher, a Protestant theologian and translator of Plato and a key figure in the development of modern hermeneutics, proposed the possibility of a universal hermeneutics, as a means for all interpretive processes (Grondin, 2003a). Although his philosophy is too extensive to be presented here, aspects that have particular importance for subsequent hermeneutics are briefly outlined. His proposal was one of a much more holistic conception of meaning than that of his predecessors (Forster, 2002). He suggested that hermeneutics was related to the art of understanding where there is one who speaks and one who hears. According to Schleiermacher, when one hears a series of words it is the method by which their meaning is understood that is the hermeneutical process (Palmer, 1969).

Although not his original conception but one that prevailed in the work of subsequent hermeneuticists and central to Schleiermacher's theory of

interpretation was the concept of the hermeneutic circle (Palmer, 1969; Lawn, 2006). Essentially, he maintained that the meaning of the whole of a text is understood in relationship to the parts and vice versa. The fundamental argument is that a text cannot be understood unless there is a sense of the whole but simultaneously the whole cannot be understood unless its constituent parts are known. Significantly, Schleiermacher, in this conception, extended interpretation beyond the semantic meaning of texts to include cultural and historical meaning. An ideal interpretation is a holistic activity whereby any given piece of text must be interpreted in the context of the whole text of which it is a part, its historical milieu, the frame of the language in which it is written and the author's individuality and psychology (Forster, 2002). Therefore, meaning is relative to context and is constantly redefined as context changes or alters (Lawn, 2006).

He further declared that an aspect of the hermeneutic circle is the gap between the meaning of the words used and the thoughts, intentions and viewpoint of the author. Schleiermacher presented this distinction as grammatical and psychological types of interpretation. Grammatical or linguistic refers to syntax, word usage and common meaning whereas psychological signifies the underlying nuances in texts not captured by grammatical interpretation. For example, grammatical interpretation does not capture intonations such as sincerity, humour or bitterness and it is these, Schleiermacher contended, that tell us something of the character of the speaker, which subsequently enhances the context for interpretation (Lawn, 2006). Central to the psychological or technical aspect of hermeneutics is the goal of comprehending the author's individuality or inner thoughts, that is, getting at the 'thinking of the speaker' (Marshall, 1987:17). Schleiermacher charges us with attempting to understand the author better than the author understood himself (Forster, 2002; Fehér, 2001). However, he also acknowledged that genuine understanding of another can never actually be achieved but is something that can be approximated only (Forster, 2002).

Ultimately, however, interpreters of Schleiermacher's hermeneutics contend that in attempting to understand the author, he failed to address the subjectivity of the interpreter, which he never saw as problematic in relation

to the subjectivity of the author (Marshall, 1987). Gadamer (2004) subsequently argued that, in making the interpreter, and all he constitutes, invisible in the face of the author's psychology, understanding could not be achieved.

Furthermore, there is a view that although Schleiermacher was the father of modern hermeneutics (Palmer, 1969), his work was concerned with a quest for method, which, according to Gadamer (2004) brings it closer to the scientific enterprise. It took the work of subsequent philosophers such as Dilthey and Heidegger to free hermeneutics from its methodological 'straitjacket' (Lawn, 2006). Whilst these are among some of pertinent criticisms of Schleiermacher's work, it is suggested here that the cultural and historical context that Marshall (1987:18) describes as the 'innocent happy dawn of hermeneutics as the philosophy of understanding' was a significant factor in both influencing and limiting his conceptions. Whilst he recognised the place of creativity in interpretation, he lived in a period when justification of the validity of hermeneutic method, in the context of a powerful rationalism, dominated.

3.4 Dilthey

Following Schleiermacher's death, Palmer (1969) claims the development of a general hermeneutics declined until Dilthey, a historian and German philosopher began to take an interest in hermeneutics as a foundation for the human sciences (*Geisteswissenschaften*). For Dilthey, the natural sciences (*Naturwissenschaften*) were concerned with cause and effect, which he deemed inappropriate for the human sciences that had understanding (*Verstehen*) at the heart of their endeavour (Lawn, 2006). Dilthey's conceptions represented a move to the broader category of 'life' interpretation (Lawn, 2006). In the final phase of his philosophy, he came to believe that hermeneutics is the theory of interpretation that relates to all human expressions of one's own, or another's human life including speech and writing, gestures, actions, paintings, institutions, societies and past events (Inwood, 1998; Makkreel, 2008).

Dilthey considered that only by developing a methodology of their own could the human studies achieve legitimacy and independence (Grondin, 2003a). He was inspired by the philosophers and thinkers, Comte and Mill who sought to make human sciences into rigorous and scientific disciplines (Rickman, 1976). However, he opposed what he considered was their narrow conception of experience and their belief that to be scientific they must follow exactly the methods of physics or chemistry (Rickman, 1976). Thus began Dilthey's life-long concern with establishing a philosophical foundation for the human sciences akin to that undertaken by Kant in his *Critique of Pure Reason* (Grondin, 2003b).

Epistemological inquiry in the human sciences, Dilthey believed, is concerned with 'knowledge of the historical world and that is always a world constituted and formed by the human mind' (Gadamer, 2004:217). For Dilthey, the ultimate presupposition of knowledge of the historical world is experience (*Erlebnis*) (Gadamer, 2004). Experience (*Erlebnis*) in the specific sense in which Dilthey uses it represents the direct contact with life that can be called 'immediate lived experience' (Palmer, 1969). Here, he is not referring to 'an' experience but something we live in and through, it is the 'living' or 'experiencing'. Experience is the reality of 'what is there-for-me before experience becomes objective' (Palmer, 1969:109). Furthermore, experience is temporal and therefore understanding of experience is also temporal (Palmer, 1969). Understanding takes place within the hermeneutic circle, a conception adopted by Dilthey from Schleiermacher (Palmer, 1969). He asserted that it is out of the meaning of individual parts that an understanding of the sense of the whole is acquired, which in turn determines the function and meaning of the parts.

The important legacy of these claims is that Dilthey laid the foundations for asserting the 'historicality' of human being-in-the-world whereby we understand the present only in the horizon of the past and the expected future (Palmer, 1969). According to Lawn (2006) this constituted Dilthey's foremost contribution to hermeneutics.

While Dilthey's contributions were seen as significant, it is generally held that he was, like Schleiermacher, a product of his time and unable to escape his quest for method. He believed that it was possible to acquire objectively valid knowledge for the human sciences despite its historical and interpretive nature (Lawn, 2006). This represented the definitive problem for Dilthey as these issues were ultimately irreconcilable. Nonetheless, the turn to a historical hermeneutics represented a critical change in direction (Lawn, 2006) and provided the inspiration for Martin Heidegger's subsequent ontological reorientation of hermeneutics.

3.5 Heidegger

Martin Heidegger, a 20th century German philosopher has been credited with the significant ontological turn of hermeneutics (Palmer, 1969). Although he is said to have moved away from referring to it in his later work, he is deemed to have freed hermeneutics from the constraints of searching for a method parallel to that of the natural sciences and proposed a radical redirection of the hermeneutic circle (Palmer, 1969; Lawn, 2006). Simply stated, he was concerned with the ontological foundation of hermeneutics, and wanted to determine ultimately that human understanding and existence are themselves hermeneutic.

However, there is general agreement that Heidegger's philosophy is very complex (Horrocks, 2000; 2002). His theses are extensive, his ideas and concepts are, at times, obscure and his elaborate vocabulary and less than ordinary use of language does not lend itself easily to interpretation and translation into English (Heidegger, 1962). Furthermore, there appears to be a lack of consensus among his proponents and detractors about his influences, his life and his philosophy. Therefore, this discourse is intentionally limited to illustrating those concepts that represent the ontological turn of hermeneutics, whilst acknowledging that, of necessity, it does not represent a comprehensive account.

3.5.1 Being

The stated problem of Heidegger's life work in philosophy was the metaphysical, 'problem of Being' (Solomon, 1985:198). He began his treatise in *Being and Time*, by appealing to the need for the question of 'Being' to be restated since, in his view, it had been forgotten (Heidegger, 1962). He argued that a dogma had developed in western philosophy whereby questioning the meaning of Being had become superfluous and neglected (Heidegger, 1962). To Heidegger, we have forgotten what it means 'to be' and what it means for us to be what we are because of an over-emphasis on epistemological matters (Inwood, 2000).

Heidegger used the concept of *Dasein*¹ to uncover the primitive nature of 'Being'. In traditional German philosophy it has been referred to as any kind of existence, but Heidegger tended to use it primarily with the narrower, everyday conception to stand for the kind of 'Being' that belongs to persons. (Heidegger, 1962:27). The second sense of 'being'² is generally translated to mean 'entity', 'thing' or 'something which *is*' (Heidegger, 1962; Horrocks, 2000). Entities tell us about the specific nature of things and investigations into them are ontical³ investigations.

Heidegger claimed that the being (entity) that has ontical priority over all other beings is ourselves, because our existence is of concern to us. It is a concern for us because our world is something we seek to understand. Therefore, *Dasein* is an entity, which does not just occur among other entities. Rather it is ontically distinguished by the fact that, in its very Being,

'that Being is an issue for it...*Understanding of Being is itself a defining characteristic of Dasein's Being*. *Dasein* is ontically distinctive in that it is ontological ' (original italics) (Heidegger, 1962:32).

¹ The etymological construction of *Dasein* is *da-sein*, which means literally 'being-there'.

² (without the capital 'B'), comes from '*das seiende*'

³ The distinction between ontological and ontical level of analysis in respect of human existence is the distinction between the existential and existentiell levels (ontological difference). The existentiell (ontic) is concerned with the **concrete** question of existence, that is, people exist through the conduit of being a mother/father, teacher, nurse. Embedded in this existentiell understanding is an existential preontological understanding of being and it is this that Heidegger wants to expose as it constitutes the ontological categories of Being that are the **same** for every *Dasein* (Horrocks, 2004).

He also suggested that in order for Dasein to be concerned with its own existence, some understanding of it must be there already. He refers to this as a 'preontological understanding of Being' and claims it is constitutive of the human kind of Being (Heidegger, 1962:32). Because of this, he proposed that we are well-placed to interrogate it by investigating our understanding (or lack of understanding) of that Being (Stolorow, 2006).

Drawing on the phenomenological method of his mentor Edmund Husserl, Heidegger proposed that phenomenology, defined as 'to the things themselves' (Heidegger, 1962:50) is a science of phenomena and therefore, any demonstration of 'an entity as it shows itself in itself' can be called phenomenology (Heidegger, 1962:58). Furthermore, because Being in every case is the Being of some being (entity), 'we must first bring forward the entities themselves if the aim is that Being should be laid bare' (Heidegger, 1962:61).

3.5.2 Understanding

For Heidegger, the possibility for understanding our Being, lies in our 'average everydayness'⁴ in the world (Cabulea, 2003). We engage in the world in a practical sense long before we seek to reflect on it (Lawn, 2006). In this sense, we have an *a priori* relation to it as 'being-in-the-world' and therefore, are inseparable from it. In addition, all human existence is grounded in time, which constitutes the 'horizon for all understanding of Being and for any way of interpreting it' (Heidegger, 1962:39). Understanding is not a cognitive inquiry but an orientation towards the way we are in the world (Palmer, 1969), which Heidegger declares is hermeneutic in nature. The world is familiar to us in a simple, intuitive way and our understanding of it is more akin to a pragmatic 'know-how', an ability. (Ramberg and Gjesdal, 2005). Through our engagement in the world, we come to a world view or perspective (Lawn, 2006). This 'fore-structure' is the implicit and background

⁴ We have three distinct but interrelated modes of engagement with our surroundings; ready-to-hand (the mode in which we do most of our everyday living -basic, atheoretical, holistic, non-reflective); unready-to-hand (the mode that we enter when we encounter a problem in our practical activity); present-at-hand (the mode we enter when we detach ourselves from practical involvement in the activity and where we may use tools of analysis or calculation in order to solve a problem) (Packer, 1985).

understanding that is always there when we seek to understand. Fore-structure has three components, namely 'fore-having', 'fore-seeing' and 'fore-conception'⁵ (Heidegger, 1962). These pre-existing interpretations represent the conditions on which we seek to understand the world and make other interpretations possible (Lawn, 2006).

At times, however, what is normally in the background is brought to the foreground or consciousness through interpretation (Ramberg and Gjesdal, 2005). Heidegger's (1962) famous example was that of the hammer, where in its dysfunction or loss, the tacit activity of hammering is no longer possible. Thus, we are awakened or alerted to a more authentic understanding of the purpose of the hammer in the context of equipment or even within the wider context of the world of work (Lawn, 2006). Therefore, interpretation makes things appear *as something* (Ramberg and Gjesdal, 2005; Lawn, 2006).

Heidegger maintains that Dasein is always and ceaselessly projecting into the future, always *becoming*, but doing so from the perspective of its tacit understanding of the present and the past (Johnson, 2000; Lawn, 2006). Heidegger describes this unity of past, present and future as temporality (Heidegger, 1962). Thus, we are always in a circle of interpretation. This hermeneutic circle, as conceived by Heidegger, is the interplay between our self-understanding and our understanding of the world and involves an existential task with which each of us is confronted (Ramberg and Gjesdal, 2005). The circle cannot be avoided; it is more a matter of getting into it properly as it contains the possibility of original insight.

In terms of hermeneutics and phenomenology, Heidegger's conceptions, sometimes referred to as 'hermeneutic phenomenology' (Palmer, 1969) represented a radical shift in focus. He declared phenomenology to be a science of the Being of entities, that is, ontology. Because it is the study of Being and there is a constant hermeneutical movement in the structure of

⁵ Fore-having (*Vorhabe*) – 'what we have in advance', approaching what is to be understood with some sense or some understanding of it already in mind. Fore-having *reveals* what is to be understood. Fore-sight (*Vorsicht*) – 'what we see in advance', focuses on *what* is to be understood. Fore-conception (*Vorgriff*) – 'what we grasp in advance', what is to be understood is already decided upon by a definite conceptualisation – related to the verb (*vorgreifen*), to anticipate.

understanding in everyday life, hermeneutics is no longer comprehended as a philological tool but has as its business the meaning of human life. As far as Heidegger is concerned, hermeneutics is an ontology of understanding and interpretation and is about the most fundamental conditions of man's being in the world (Palmer, 1969; Ramberg and Gjesdal, 2005).

3.5.3 Heidegger and this study

At this point of my exploration, I considered that Heidegger's hermeneutic phenomenology might provide a suitable philosophical underpinning for the intended study. The research question seemed compatible with a study using Heideggerian philosophy in that it focussed on the meaning of living with chronic pancreatitis. However, my reading of Heidegger's work and the interpretations by others brought to the fore and presented a challenge to my own conception of 'meaning'. After considerable reflection, 'meaning' in the sense in which I intended was about 'significance' and 'implication' based on my belief that the dysfunctional body in chronic pancreatitis would be a significant concern (issue) and have implications for those living with it, in terms of their altered everyday living, how they chose to live their altered lives and their future existence. The foundation of this belief was located in my ontical understanding of being a nurse but also situated in a primordial understanding of the imagined implications of chronic pancreatitis for my own existence and by implication, that of others.

However, while it seemed that there were some parallels between my conception of 'meaning' and Heideggerian thought, particularly in respect of a concern for human existence, I judged that there would have to be congruency also with the overall purpose of the study. It was at this juncture that I considered the issue of adopting Heidegger's philosophy to be complex and perplexing. Horrocks (2000; 2002) contends that Heidegger's purpose in hermeneutics was not to focus on everydayness for its own sake but as a way of revealing the essential structures of Dasein, that are the *same* for every Dasein and then, hopefully, reveal the meaning of Being in general (Horrocks, 2000). He goes on to say that while Heidegger starts his study in everydayness, he does not want to reveal the shared meanings of human actions that vary across cultures (Horrocks, 2004).

Yet, the central focus in the proposed study was explication, interpretation and understanding of the everyday, culturally situated and contextualised lives of the participants in order to bring their plight to consciousness. Therefore, whilst it cannot be said that the possibility for self-understanding did not exist through enabling the participants to give voice to their illness experience, the overall purpose was not ontological in the absolutist sense in which Heidegger explicates it. Therefore, I began to question whether or not using Heideggerian principles for the purpose of the study would constitute a methodological error.

In turning to the nursing literature for clarification I found limited support for my contention that this concept of ontological difference (Heidegger, 1962) was significant in determining whether or not a study was Heideggerian. It seems that in the process of attempting to apply philosophical principles to the practical activity of research, nursing studies and theories that claim to base their inquiries on Heidegger's philosophy select, modify or adapt aspects of it (Dowling, 2007). This has drawn criticism in the research and academic literature about the 'correct' or rigorous use of 'phenomenology' and/or Heideggerian philosophy (Draucker, 1999; Giorgi, 2000a; Giorgi, 2000b; Caelli, 2001; Horrocks, 2000; Horrocks, 2002; Horrocks, 2004; Dowling, 2007), with the result that it has been difficult to elucidate my own understanding and interpretation. However Giorgi's (2000a; 2000b) argument regarding the use of Husserl in nursing research has some resonance with the issue of following Heidegger. He claims that in order for philosophy to be relevant for praxis, researchers must be aware of the need to modify it if it is to have any meaning in the context in which it is to be used. Therefore, whilst acknowledging that there are questionable examples of the use of Heidegger's philosophy amongst nursing researchers, it appears that elucidation of the principles adopted and demonstration of the influence in the execution of the study are the issues of paramount importance.

Thus the matter became one of determining whether adopting Heideggerian principles would enable the meaning of living with chronic pancreatitis to be uncovered. Two issues that emerged were the use of interviews and my role as interpreter of the participants' discourse. In respect of the former, Packer

(1985) states the ready-to-hand mode of engagement is the starting place for a hermeneutic inquiry. Studying what people do when they are practically engaged in life is the primary source of a researcher's understanding (Packer, 1985). Both Packer (1985) and Addison (1989) suggest this is best achieved through observation because, in their view, ready-to-hand mode can become present-at-hand mode in the context of an interview.

However, for ethical and practical reasons, I recognised that observing participants in their everyday living was not possible in this study. Therefore, given the research question, interviews were the proposed method of data collection. I conceived that they would facilitate the participants' articulation of living with chronic pancreatitis. However, I now acknowledged that it was likely the participants would move from the ready-to-hand to the present-at-hand mode because an element of reflection would be introduced in the very asking and in the inevitable contemplation between interviews. Therefore, the focus of the study was not the ready-to-hand mode per se but the participants' exposition of it.

Consequently, the interlocution of the interview would become the basis for an understanding of the subject matter following which the transcribed text would be the grounding for my interpretation. Ultimately, an understanding of the meaning of living with chronic pancreatitis would be constructed from the interpretation. Following these insights, I deemed the dialogue between the participants and myself to be fundamental. As a result, I began to examine the work of Hans-Georg Gadamer who placed language and dialogue at the centre of his philosophical hermeneutics.

3.6 Gadamer

Hans-Georg Gadamer (1900-2002) has been described as one of the most important figures of 20th century thought in respect of his philosophical hermeneutics and because his long life made him a privileged observer of that century (Grondin, 2003a). Grondin (2003a) goes on to suggest that it was the publication of his magnum opus *Truth and Method* in 1960 that established him as an independent thinker and moved him out of the shadow of his mentor Heidegger. He is seen to have extended Heidegger's re-conception of

interpretation and understanding by bringing it to full systematic expression (Palmer, 1969; Godrej, 2004). Moules (2002) offers that Gadamer reclaimed, restored and conserved the history of metaphysics that Heidegger dismantled. Although there is no question that Gadamer's philosophy is closely tied to that of Heidegger, Grondin (2003b) claims that his theses in *Truth and Method* were a reply to Dilthey, whose thought represented the latest advance in philosophical hermeneutics. Thus, it has been suggested that Gadamer's hermeneutics of understanding can only be understood in opposition to Dilthey's methodological hermeneutics (Grondin, 2003b). It was in Gadamer's hands that hermeneutics became concerned with the nature of understanding in its universality. The combination of his background in classical philology combined with the Heideggerian influence led to a new philosophical hermeneutics based on the ontology of language (Palmer, 1969).

Gadamer's philosophical hermeneutics is deemed to have taken hermeneutics into the linguistic phase with his assertion that 'Being that can be understood is language' (Gadamer, 2004:470; Lawn, 2006). In order to situate this declaration some explication of Gadamer's conception of and conditions for understanding are presented. However, throughout his life, Gadamer was a prolific writer with the result that a detailed analysis of his extensive works is not possible. Therefore, the discussion is confined to those aspects that have significance for the study in hand.

3.6.1 Understanding

Gadamer's basic idea of understanding is complex and according to Grondin (2002) has many different meanings. Ultimately, however, his conception can be seen as one of 'application'⁶. He suggests that every understanding

⁶ His idea is a unity of three conceptions of understanding that are cognitive, practical and linguistic and are summed up in the notion of 'application' (Grondin, 2002). The verb to understand (*Verstehen*) in German refers to the cognitive and epistemological sense as well as the sense of a practical activity. Whether a person understands cognitively or practically they have, in common, the idea of being 'well versed' in something. In a linguistic sense he suggests that understanding an 'expression' is to know what is and is not disclosed. This is referred to also as 'one knows one's way around in it' (*sich auskennt*). Understanding is ultimately inseparable from oneself and therefore all understanding is self-understanding (*sichverstehen*) in the sense of 'knowing one's way around' (Gadamer, 2004:251). Gadamer also emphasised the connection between *Verstehen* and *Verständigung*, which translates as 'coming to an understanding with someone', or 'coming to an agreement with someone' and *Einverständnis*, 'understanding, agreement, consent' (Gadamer, 2004).

requires the effort of application of what is understood to the present and that every understanding has at its root the application of meaning. In this, Gadamer's conception of application is akin to 'translation' (Grondin, 2002), which implies an act of interpretation. For Gadamer, understanding and interpretation are ultimately the same thing (Gadamer, 2004). That which I seek to understand always needs to be translated and when I understand something it means it can be translated into my own words thereby signifying its application to my situation. Understanding is a mediation or translation of past (particular to textual interpretation) meaning into the present (Gadamer, 1976). Implicit in Gadamer's concept of understanding is its fundamental connection with language (Gadamer, 2004).

3.6.2 Language

Gadamer's views on language are in accord with the expressivist tradition, which is a paradigm of language that is concerned with 'the power of language to express, specifically the power to express what it is to be human' (Lawn, 2006:78). This goes beyond the notion of language as representative or merely as a means of conveying and receiving information. Central to the expressivist view is that any statement says more than it says. When saying what one means, it is held together in a unified whole with what is 'unsaid' and is understood in this way (Gadamer, 2004). Furthermore, in the saying it presupposes a common and shared human world without which we would not be able to communicate (Lawn, 2006). In fact, Gadamer takes this further by stating that 'language is not just one of man's (*sic*) possessions, rather on it depends the fact that man has a *world* at all' (Gadamer, 2004:440). Man is a being who 'possesses language' and because of this ability to communicate, common meaning and common life is possible (Gadamer, 1976). For Gadamer then, we are thoroughly involved with and inextricably bound in language, that is, 'possessed of language' and it is through language that the world is opened up for us (Ramberg and Gjesdal, 2005; Lawn, 2006).

3.6.3 Dialogue/conversation

Fundamental to Gadamer is that language has its true being in dialogue or conversation. In a 1993 interview, Gadamer said his contribution has been to

move the idea of conversation to the very centre of hermeneutics (Vessey, 2006). Dialogue for Gadamer, in the spirit of Socrates and Plato, is an intense, restless and unending quest for truth (Palmer, 2001). 'Language is the medium in which substantive understanding and agreement take place between two people' (Gadamer, 2004:386). Although he refers here to 'two people', he also spoke of 'texts'⁷ that are to be understood. To understand a written text, we must engage with it in a dialogue, a conversation (Lawn, 2006). Texts are fixed expressions of human life and different from a conversation between two people in that the text speaks and is given meaning only through the interpreter. Nonetheless, like a conversation between two people it is the subject matter (*Sache*)⁸ that binds the text and the interpreter. The *Sache* comes to presence and presentation in conversation. Therefore, all dialogue or conversation is about something (Gadamer, 1976; 2004).

This notion of conversation being *about* something is central to Gadamer's idea of the hermeneutical conversation in which there is equality and reciprocity between the partners who are both concerned with the subject matter. The hermeneutic conversation begins when the interpreter genuinely opens himself (*sic*) to the 'other' person or text (Gadamer, 1976). In the art of conversation, the other person is with us. Placing oneself in openness is recognising that one wants to know but simultaneously recognising that one does not know. Central to wanting to know is the essence and priority of the *question* (Gadamer, 2004). Conversation that is intended 'to reveal something requires that the thing be broken open by the question' (Gadamer, 2004:357). Fundamental to openness is not simply gaining an answer to the question but acknowledging the indeterminacy of the question and the further questioning that is posed by the text. Thus, dialectic proceeds by way of question and answer. Conversation is about 'how to speak to someone and how to answer someone' (Vessey and Blauwkamp, 2006:358). The answer is not a given, there is no finality to the interpretation but new possibilities and

⁷ Gadamer's conception of text is not limited to the written word. Although he was a philologist and concerned with traditional hermeneutics, he made reference to other forms of text such as works of art and dramatic productions.

⁸ The German *Sache* refers more to the idea of 'point', 'the thing to be debated' or 'the thing that matters' rather than the notion of the 'the thing in itself' (Grondin, 2003b:85)

new understandings emerge that were not there before the question was asked (Gadamer, 2004; Binding and Tapp, 2008). Therefore 'we understand in a different way, if we understand at all' (Gadamer, 2004:296). These conversations with people or with texts leave something behind in us and transform us in some way.

3.6.4 Horizon

However, Gadamer states that the openness of a question is not boundless as it is limited by its horizon. In this Gadamer invokes several interrelated concepts that include tradition, horizon and prejudice. Essentially, he proposes that we are historical beings. 'History does not belong to us, rather we belong to it' and understanding is both '*effected*' and '*affected*' by it (Gadamer, 2004:278). Thus, understanding always takes place against the background of our history. Consciousness or awareness of 'being effected' by history (historically-effected-consciousness – *wirkungsgeschichtliches Bewußstein*) is, according to Gadamer, identical with awareness of the hermeneutical situation, which is also referred to as a 'horizon'⁹. It is through learning a language and being part of a culture that we develop a perspective of the world, a horizon, which is the 'range of vision that includes everything that can be seen from a particular vantage point' (Gadamer, 2004:301). Therefore, understanding and interpretation always happen from within a particular horizon that is determined by our historically-determined situatedness (Malpas, 2008). What this means essentially is that our belonging to history and the manner in which we engage in our everydayness in the world is created by the community in which we interact and the traditions embedded therein.

3.6.5 Tradition

The specific cultural milieu in which people are embedded is tradition (Lawn, 2006). It is something in which we stand and through which we exist although, for the most part, we are not aware of it (Palmer, 1969). The present is seen and understood through that which has been handed down

⁹ The term horizon denotes a certain 'generosity of spirit' and 'wisdom'. Wisdom is central to Gadamer's concept of horizon (Grondin, 2003b).

from the past while, at the same time, the past can only be understood from the perspective of the present. Thus, tradition forms the present and is handed on so that it also shapes the future (Geanellos, 1998). Furthermore, because we live in and through language, it is the medium by which tradition is communicated and expressed but it is also where tradition is hidden (Palmer, 1969). Language is the repository of a culture wherein its thoughts and thought forms are revealed and concealed (Palmer, 2007).

3.6.6 Prejudice

Because we are historical and are in a tradition we develop prejudices. Gadamer rehabilitated this concept from the modern and negative connotation of unreflective or overly impulsive decisions and defined it as 'a judgment that is rendered before all the elements that determine a situation have been finally examined' (Gadamer, 2004:273). Our prejudices are the pre-judgements that, for the most part, we silently and unreflectively acquire through our everyday acts of being in our world (Lawn, 2006). Gadamer argues that all understanding inevitably involves some prejudice and is therefore, a condition of understanding. Although they can sometimes distort, prejudices are not necessarily false judgements as they can have both positive and negative values. Furthermore, our prejudices open us up to the world and enable us to grasp, in a preliminary fashion, that which is to be understood (Gadamer, 2004).

However, Gadamer warns that hidden prejudices can hinder us from understanding the subject matter. When we bring our prejudices to our conversations, there is the possibility that we may not be aware of some of them. Yet, he contends, that prior to engaging with the text we must endeavour to exclude anything that will impede our understanding (Gadamer, 2004). We must make conscious 'the prejudices that govern our own understanding', which enables the meaning of the 'other' (or text) to be isolated and valued on its own (Gadamer, 2004:298). Gadamer acknowledges that foregrounding prejudices that are unnoticed is impossible but proposes that when we encounter or are addressed by something that we seek to

understand, they are provoked¹⁰. As our prejudices become evident they can, in turn, become the focus of further questioning and are capable, subsequently, of being revised (Gadamer, 2004). An important point here is that revising or correcting an illegitimate prejudice is always only made in light of a new one, which replaces it (Grondin, 2003b). Our horizon is not fixed and it is constantly changed and modified by a process of expanding or opening up of new horizons (Gadamer, 2004; Lawn, 2006).

In this, Gadamer emphasised the tentative nature of understanding. We begin with provisional anticipations, which are revised the more we engage with the subject matter. Whenever we understand, we are involved in a dialogue that encompasses both our own self-understanding and our understanding of the matter in hand (Malpas, 2008). The hermeneutic experience is the experience that our anticipations are shattered (Grondin, 2002). True experience, in the Gadamerian sense, must lead to openness to even newer experience and the experienced person is able to tolerate the possibility of plurality of interpretations (Grondin, 2002).

3.6.7 Fusion of horizons

This process of coming to an understanding was identified by Gadamer as a fusion of horizons (*Horizontverschmelzung*) (Gadamer, 2004). The horizon of the interpreter and the person or text are fused through dialogue/conversation so that a new understanding (agreement) about the subject matter emerges. This is an understanding based on a shared perspective. However, because understanding is an on-going process and our horizons are ever-changing fusion is never completely elucidated or final (Malpas, 2008).

3.6.8 Hermeneutic circle

These movements and the processes that occur in understanding and interpretation constitute Gadamer's conception of the hermeneutic circle. In

¹⁰ Here Gadamer (2004) also refers to 'temporal distance', that is, time can 'often' act as a filter for ill-founded judgements to disappear and to enable 'true' and 'false' prejudices about a text/piece of art to be distinguished. This concept has been subject to some criticism as temporal distance can also obscure (Grondin, 2003b).

adopting the metaphor of a circle, he recalls the hermeneutic rule that 'the whole must be understood in terms of the detail and the detail in terms of the whole' (Gadamer, 2004:291). This principal, which he states stems from ancient rhetoric and adopted in modern hermeneutics is a circular relationship. However, the circle is not a methodological one but because it is rooted in our being-in-the-world is one that describes an aspect of the ontological structure of understanding (Gadamer, 2004). The essence of the ontological character of the circle is that every interpretation inevitably draws on anticipations of understanding, tradition and prejudices and throughout the process there is continuous critical reflection (Grondin, 2002; 2003b). The constant revision of anticipations of understanding is the search for coherence between the parts and the whole with the overall objective of perfection (Grondin, 2002; 2003b). One is involved already in the hermeneutic circle (Godrej, 2004) and to understand is, above all, the ability to listen to each other about the subject matter (Vessey, 2006). To Gadamer, there is a particular dialectic implied in hearing (*hören*), which is associated with a sense of obligation to respond because something has been heard. Once you have heard something you cannot turn away from it and you belong to it because you have been addressed by it (Gadamer, 2004).

3.6.9 Gadamer and this study

Coming to Gadamerian hermeneutics as the philosophical underpinning for this study was itself an intense dialogical process of question and answer. Unravelling the meaning of his concepts was a complex task and throughout the process, although I experienced moments of insight I was also beset with confusion and I constantly questioned my understanding and interpretation. Ultimately, however my experience resonated with that of Moules (2002) who suggested that whilst acknowledging the many 'voices' of hermeneutics, in the end we make choices about those philosophers who speak loudest to us and whose philosophies fit best with our beliefs and practices. Finally, I concluded that my conversations with Gadamer, and by association Heidegger, had a profound effect, not just on my understanding of hermeneutics but on my understanding of myself as a person who is a nurse and a researcher about to explore what it means to live with chronic pancreatitis. Ultimately, however, Gadamer's voice spoke loudest because of

the focus in his work on the dialogical nature of understanding and what happens in the event of understanding. He seems to avoid the absolutism of Heidegger by offering conditions for understanding, which I considered could provide guidance and direction in undertaking the study. This sense of 'fit' with Gadamer's philosophy and its manifestation in the study is explored by examining how the researcher is positioned in seeking understanding, how engagement with the subject matter is undertaken and how meaning is finally constructed.

3.6.9.1 Positioning the researcher

Prior to seeking a philosophical framework that would guide the study, I maintain that my involvement had been determined already. By posing the question, 'what does it mean to live with chronic pancreatitis?' I had deemed that it was a matter that was important to me. Therefore, in Gadamerian terms the work of understanding had already begun. Whilst it was a subject about which I knew 'something', there was a sense that my knowing was limited to my perspective. There was an implicit awareness that in posing the question to those who live with the condition, a different perspective could be brought to the fore. Embedded in this belief was my previously stated view that accessing patients' experiences through qualitative research, was valuable in enabling us to practice better.

Yet, it was only through engaging with hermeneutics and ultimately Gadamer that I was able to identify that 'hidden' in my perspective are prejudices or pre-judgements about chronic pancreatitis and those who live with it. Thus, Gadamer's directive to bring prejudices to the fore stimulated a return to my rationale for the study and the subsequent literature review. In so doing I was able to bring to light, through examination of my tradition and horizon what I now identified as emotional, social and cognitive pre-understandings. These are explicated in the following chapter.

Confronting the prejudices and pre-judgements, to the extent that it is possible, that exist because of who I am in terms of my culture, tradition and experiences has raised my awareness of their influence. They represent my orientation to the world and they situate my understanding. However, in

philosophical hermeneutics, rather than setting them aside they must be kept in view throughout the study as they are fundamental not only in how I approach my interactions with the participants but also in how I interpret and construct the meaning of living with chronic pancreatitis. Furthermore, engagement in the research has the potential for my prejudices to be challenged or for those that are unforeseen to emerge. There is also the ever-present possibility that they will be revised and replaced as my horizon expands through my encounters with the 'other'.

Therefore, in philosophical hermeneutics my involvement in the research inquiry is implicit but nonetheless governed by my prejudices. For this reason, it is essential that I adopt a position of critical reflection and constant questioning of what it is I understand about the subject matter, throughout my encounters with the participants. This stance will facilitate my being open and ready to receive what they have to say in order to gain a different understanding.

3.6.9.2 Engaging with the subject matter

As indicated above, Gadamer claimed that understanding is achieved primarily with and through 'others' and the basis for understanding between two or more people is genuine conversation or true dialogue. Therefore, I considered that his concepts of language and dialogue/conversation offered guidance for how I would 'be' in my interactions with the participants in the study. In genuine conversation, Gadamer (2004) proposes that the participants become involved and are led by the subject matter. The conversation follows its own twists and turns and as it proceeds, further questions are posed and answered but always with the possibility of further questioning. Although its outcome or where it will end cannot be predicted, it is in genuine conversation that the horizons of the participants in the dialogue are fused so that new understanding about the subject matter, beyond what existed previously, occurs (Gadamer, 2004).

As the vehicle through which data collection would happen, I was thus charged with creating the conditions that would maximise the possibility for genuine conversation. I believed that these would be achieved by focussing

on the subject matter, being aware of my own position, being open to the participants' position, maintaining a questioning stance, tolerating difference and ambiguity and attending to, listening to and hearing what they had to say.

Yet, underlying these intentions was a tension concerning Gadamer's assertion that understanding is tentative and transient with the potential for different understandings always existing. How would I determine then, when and if understanding of the topic could be said to have been achieved or even if I had failed to understand?

According to Gadamer, 'the harmony of all details with the whole is the criterion of correct understanding. The failure to achieve this harmony means understanding has failed' (Gadamer, 2004:291). If the premise is adopted that the final construction of the meaning of living with chronic pancreatitis is the 'whole' in this inquiry, then there should be coherence or harmony with its constituent parts. Its parts, in this context are the understandings achieved with each of the participants in the study.

However, in order to facilitate coherence between these parts and the whole, I would suggest that the process begins at the level of the individual encounter with each participant. This would necessitate accepting each conversation as a 'whole' constituted of its parts, that is, the spoken word. If harmony and coherence is aspired to at the level of the individual then it is more likely to be achievable in the final construction of meaning. It is my assertion however, that this may not always be attained in one conversation, even if it achieves the level of the genuine. Therefore, engaging in more than one conversation with each participant is more likely to achieve coherence, although it is never guaranteed.

3.6.9.3 Constructing meaning

As outlined earlier, the focus of the study is the participants' exposition of their everyday, culturally situated and contextualised lives with chronic pancreatitis, and dialogue or conversation will form the basis of articulating those experiences. However, an important factor in coming to the research

question and my position as a researcher who was involved, was how these experiences would be translated in the final analysis, to meaning. I recognised that the focus of the study was not a description of the pure experience but what it meant. Although Gadamer did not provide a method for constructing meaning, his conception of understanding as 'application' provided some direction for the hermeneutic task of translating the participants' experiences into a construction of meaning.

He asserts that the interpreter's task is not simply to repeat what is said in the conversation but to make one's own what the text says (Gadamer, 2004). As stated in the outline of his conception of understanding, this means that when I understand something it can be translated into my own words, thereby signifying its application to my situation. This, I contend, is made possible because I am involved and it is through me and my understanding that the multiple constructions and realities of the participants' stories of living with chronic pancreatitis will be uncovered. Ultimately, then, the final interpretation is mine but is one that carries with it the responsibility for presenting as complete and faithful a representation of the subject matter as is possible.

Since, in Gadamerian terms, the objective is to manifest textual meanings, the audio recordings and transcriptions of the conversations are central to the interpretive process because these 'texts' are the concrete expressions of the participants' recounted experiences. By fixing these expressions in writing they become the means by which ongoing genuine conversations are made possible. Furthermore, texts are available for interpretation and re-interpretation at any time and it is through them that examination of the parts is facilitated thereby providing the platform for determining harmony and coherence with the whole.

Key to translating these texts to meaning is the aspect of Gadamer's metaphor of the hermeneutic circle that claims every interpretation inevitably draws on anticipations of understanding, tradition and prejudices and during the process there is continuous critical reflection. Therefore, throughout the process of constructing meaning the aim is to work towards a fusion of the

horizons of the text, the researcher and the participants. Early understandings of the stories of the participants will be expanded upon through dynamic engagement with the texts, reading/re-reading, critical reflection and writing. Adopting such strategies will enable me to account for the emerging meaning but will also provide a safeguard against making too early a projection.

In the final analysis then, the choice of philosophical hermeneutics as the underpinning for this study was located in my belief that in the practice of nursing and being a nurse, things address us. By virtue of being addressed, they are rendered important and we are obliged to hear and listen. Engaging with those who are the focus of our practice challenges us. Through dialogue there is the possibility that we can learn, gain understanding and develop our practice. In this study, encountering the other's 'truth' about living with chronic pancreatitis can awaken new understandings because it has not been explored previously in this way.

3.7 Conclusion

This chapter outlined my emergent understanding of modern hermeneutics and ultimately, my proposition that philosophical hermeneutics, after Gadamer, is an appropriate underpinning for constructing an understanding of what it means to live with chronic pancreatitis. The evolution of modern hermeneutics through the work of Schleiermacher, Dilthey and Heidegger provided the backdrop for understanding the work of Gadamer. Particular attention was paid to Heidegger's ontology, not only because his work represented a significant turn in hermeneutics but also because of his influence on Gadamer's work. Within this chapter I outlined what I understood to be the key concepts in Gadamer's philosophy that have relevance for the proposed study whilst recognising that they do not constitute a complete review of all of his work. I explored also how these concepts, whilst not offering a structured method for achieving understanding, offered some direction in how the researcher is positioned, how the subject matter might be engaged and how meaning might be constructed. Finally, philosophical criticisms of Gadamer's work such as a charge of relativism (Palmer, 1969; Lawn, 2006) were assimilated and considered during the process of gaining an understanding but ultimately, I came to believe that it is the elucidation of

how his principles would inform the execution of this research study that was of paramount importance. Consequently, the following chapter is an account of how the methodology was operationalised in this study.

CHAPTER 4 – METHODS

4.1 Introduction

This chapter discusses the process of operationalising the study based on the philosophical framework outlined in the previous chapter. It begins with a brief overview of the research question, aim and objectives and follows with a consideration of my prejudices regarding the subject matter. I then discuss the means by which the sample for the study was identified and accessed and how data collection and data analysis were undertaken. Ethical integrity is addressed and the chapter concludes with a discussion of the overall integrity of the study.

Given the reflexive nature of hermeneutics and this study, my reflections, as I engaged with the process of implementing the study, are interwoven throughout. These reflections were a key element in my decision-making and fundamental to how I met the challenges, identified possible limitations and progressed the study.

4.2 Research question, aims and objectives of the study

The research question for the study was identified as;

'what does it mean to live with chronic pancreatitis?'

In order to provide an answer to the question, the overall aim was to develop an understanding and construct a meaning of living with chronic pancreatitis and in so doing, to:

- Illuminate the everyday contextualised and culturally situated lives of the participants;
- Explicate the meaning of living with chronic pancreatitis as a basis for understanding and interpretation by others;

- Extract from the new understanding issues that may have implications for healthcare professionals and the practice of caring for those who live with chronic pancreatitis;
- Identify recommendations for enhancing the care of those with chronic pancreatitis;
- Develop recommendations for expanded understandings through further research.

As indicated in the previous chapter, in determining the question and setting the objectives, the work of understanding had already begun. Furthermore, although the objectives were broad, they represented what Gadamer (2004) refers to as my 'anticipations of understanding'. Essentially, they indicated that through explication of the everyday contextualised and culturally situated lives of the participants, a different understanding of living with chronic pancreatitis was possible. Moreover, they highlighted my general assumption that there were issues in their living that had implications for the care that they received and for the practice of healthcare professionals charged with delivering that care.

4.3 Prejudices/Pre-judgements

Embedded in these 'anticipations of understanding' were the cognitive, social and emotional prejudices or pre-judgements regarding the subject matter. Although I do not claim to have accessed all of them, I believe that bringing them to the fore prior to commencement of the data collection phase enabled me to acknowledge their influence on, and throughout, the conduct of the study.

The process of raising my prejudices to consciousness involved a question and answer dialogue, with the text, of my rationale for the study presented in the introductory chapter and the subsequent literature review as I believed they constituted the written manifestation of my beliefs, values and understanding about chronic pancreatitis and those who live with it. Through this process, I concluded my prejudices were a composite of:

- my propositional knowledge of chronic pancreatitis

- my experiential knowledge of caring for those with chronic pancreatitis
- my social knowledge of the culture of Ireland and the place of alcohol consumption within it
- my emotional and personal knowledge of the perceived impact of a chronic and progressive condition on one's living.

The final part of the process was an explication in writing of those prejudices I was able to identify at the beginning of the study. A synopsis is presented below.

For me, the prejudice or pre-judgement that underlies all others and one that has emerged through critical reflection on the focus of this study and engagement with hermeneutics is that a valuable human existence is a foundational belief and principal driver for my practice as a nurse and educator. Embedded in this is my belief that quality of life has at its core quality of human existence, and illness challenges or compromises one's ability to have a valuable existence. Furthermore, I believe illness creates existential questions for those experiencing it and in illness the matter of one's existence is raised to consciousness.

I conceive chronic pancreatitis to be a devastating and debilitating condition that has significant physiological, social and emotional consequences for those living with it. Its inexorable progression and pathophysiology leads to symptoms that are physically distressing. The pain of chronic pancreatitis is often unmanageable and treatment options have limited success. Physical debilitation is an inevitable consequence despite the efforts of healthcare practitioners and the person with the condition.

This belief has been verified by my experience of caring for those who were hospitalised with chronic pancreatitis. The long and frequent hospitalisations associated with the medical and surgical management strategies, the severity of acute exacerbations and the inability to resolve pain satisfactorily were traumatising and frustrating for the patients. Staff caring for these patients often experienced guilt and frustration associated with being unable to ameliorate the effects of the physiological assault.

Yet my experiences also generated a sense of discomfort with what I deem to be underlying stereotyping and stigmatising of patients with chronic pancreatitis. Because of a well-publicised association with alcohol, patients were, at times, labelled 'alcoholics' with the result that healthcare effort was tinged with the sense that they would continue to consume alcohol and therefore, treatment was in vain.

Directives to abstain from alcohol were the focus of healthcare advice to patients. Assessment on subsequent re-admissions to hospital included searching for evidence of 'cheating', that is, surreptitious consumption of alcohol. Furthermore, when patients claimed they had not consumed alcohol, there was a sense that they were not being truthful.

Through this, I have identified that I consider the association with alcohol as one of the reasons why I believe this group of people are marginalised by healthcare professionals. It is my belief that alcohol induced conditions do not provoke sympathy and they are deemed to be largely self-induced. Whilst these issues of labelling and stereotyping create a discomfort in me, I have become aware that I subscribe also to the tenet that alcohol and alcohol dependence are key factors in the development of chronic pancreatitis. Allied with this is an assumption that those with alcohol dependence know they are stigmatised and in respect of this study, will not participate because of a perception that they will be judged.

I believe also that chronic pancreatitis is considered less 'important' than many other conditions both within the medical and nursing world and within wider society. There is a dearth of broad-based or lay literature on the matter with publications being confined, largely, to medical gastroenterology. Why it is considered less important is difficult to determine but my sense is that it may be because of its relatively low incidence and/or its association with alcohol. Moreover, my perception that little is known about it has been reinforced by the puzzled responses I receive continually from professionals and lay people alike when I outline the focus of this study. To a certain extent, this has rendered it more difficult to justify the study and resulted in

an emphasis in the literature review on the dangers of alcohol for young people in our society.

This highlighted my associated prejudice that social life in Ireland centres on alcohol and alcohol consumption. Recent reports that the level of alcohol consumption in Ireland is high have served to reinforce this belief. Therefore, I think that abstinence is difficult for those with a dependency particularly in a society where it would not be regarded as the norm. Consequently, I assume that people with chronic pancreatitis will continue to consume alcohol despite the known risks.

However, through foregrounding these prejudices I am aware now that I do not 'know' this. My experience of caring for those with chronic pancreatitis is limited to acute management in a tertiary referral centre outside of Ireland. Furthermore, I can only imagine the psychological and emotional impact of permanent losses by relating to losses within my personal life. For this reason, I recognise that I have little insight into the daily living practices of those living with the condition. I do not know about their perception or understanding of the condition nor do I know how they manage, how they access services, what services are available or their conception of the service provision. My 'unknowing' has provoked the desire to know.

Although these constituted the prejudices I was able to identify at the beginning of the study, I recognised that engagement with the participants might bring to the fore others that were unanticipated.

4.4 Sample

In keeping with the central tenet of philosophical hermeneutics that the subject matter is central to a conversation between two people, the sample for the study was purposeful. Purposeful sampling is used in qualitative research and is based on the premise that the selected individuals can inform or represent the central phenomenon of the study (LoBiondo-Wood and Haber, 2006; Creswell, 2007). In this study, purposiveness was related to the topic for the research and was, therefore, criterion based in that all of the potential participants had been diagnosed, and were living, with chronic

pancreatitis. The sample for the study was drawn from a population of all patients (approximately 75) who, at the time of the commencement of the study were under the care of a hospital-based consultant. The population was diverse and included those who lived locally and those who had been referred from regional hospitals in all areas of the Republic of Ireland.

4.5 Gaining Access

Prior to submitting a formal application for institutional and ethical approval to undertake the study, a meeting was arranged with the consultant in charge of the care of the patients from whom the sample would be drawn and with the Pancreatic Biliary Nurse Specialist who was a member of the team. At this meeting, information on the study was provided, permission to access the sample was granted (see Appendix 1) and rules of access clarified. An application for institutional approval was submitted and granted by the Research Ethics Committee of the hospital (see Appendix 2).

4.6 Exclusion criteria

Patients excluded from this study were those who were

- a) patients considered by the medical or nursing practitioners to be too ill
- b) unable to communicate in English
- c) under 18 years of age.

4.7 Recruitment

In the first instance, it was agreed that the Pancreatic Biliary Clinical Nurse Specialist would act as professional gatekeeper and access to potential participants would be through her. An Information Sheet (see Appendix 3) encompassing an invitation to participate in the study would be distributed to patients who were admitted as in-patients or who were attending for an outpatient appointment. In-patients considered too ill would not be approached until the acute phase was considered, by the medical and nursing team, to be resolving. Patients interested in participating were asked to complete an 'expression of interest' slip, with contact details, and return it in

a stamped addressed envelope to the gatekeeper who agreed to forward it, unopened, to the researcher.

During this initial phase between September 2005 and May 2006, 14 Information Sheets were distributed. Six patients expressed an interest in participating and four of those were successfully recruited to the study. This was seen as a poor response and was attributed, in the main, to the random nature of approaching patients in a time-limited setting such as the outpatients department and the conception by the clinical nurse specialist that in-patients may not consider participation in a study a priority.

Following a further meeting with the hospital consultant, it was agreed that the Information Sheet would be sent by post to all patients with a diagnosis of chronic pancreatitis. A meeting with the Pancreas Data Controller highlighted that a database consisted only of data entered in the previous year. However, through contact with the Hospital In-Patient Enquiry Data Controllers, it was possible to construct a list of patients with a principal or secondary diagnosis (using ICD-9 coding) of chronic pancreatitis who had been admitted in the previous two years. Although patients who had not been in-patients in that time were not captured, the data controller was able to distribute, by post, a further 33 Information Sheets. 'Expression of interest slips' (see Appendix 4) were returned directly to the researcher. A further eleven patients expressed an interest in participating and ten of these were successfully recruited to the study between May and September 2006.

Of the 14 participants, 10 are male and 4 female and they range in age from 26 to 58 with seven aged 40 years or under. Six of the participants are married (four male and two female) with the remaining eight being single. Five of these participants live with family or friends while three live alone. Seven of the participants have been diagnosed with chronic pancreatitis for two years or less. Four have lived with the condition for between two and five years whilst the remaining three have been diagnosed for more than five years. Participants are distributed nationally with eight of the fourteen originating from geographical locations outside the immediate locality served by the hospital.

4.8 Data collection procedures

In keeping with philosophical hermeneutics and the overall purpose of the study the pivotal source of data was multiple, unstructured, audio-taped interviews/conversations with each participant. These conversations were synonymous with what Rubin and Rubin (2005) describe as responsive interviews where each person in the conversation is acknowledged, the relationship between the researcher and the participant is central and the contribution of each to the exploration of the subject matter in the context of their own living is recognised. Furthermore, these in-depth conversations were seen as a means of accessing rich data about the subject matter.

As stated in the previous chapter, Gadamer (2004) argues that the criterion for achieving a correct understanding is a harmony of all details with the whole. Although I could not predict with any certainty the number of interviews that would be needed to achieve a correct understanding of the subject matter, I anticipated that I would meet with each participant on two or three occasions over a period of four to six months. Although the time period was primarily associated with the practicalities of interviewing, transcribing, return of transcripts and arranging further meetings, there was the added advantage that it facilitated a more holistic view of the participants' lives, covering as it did more than one isolated time. Nonetheless, I was concerned that through the process of interviewing and returning to the participants, gaining new understandings could go on indefinitely and saturation was unlikely to be achieved. Ultimately, I had to trust that through collaboration with each participant we would 'know' when it was the correct time to stop data collection.

Supplemental biographical and contextual data were collected also in order to situate the participants' experiences. As these were collected during the audio-taped interviews, the information was extracted and a separate file constructed for each participant.

In addition, respondents were offered the opportunity to participate in the study through diary writing. Diaries have been used in a variety of ways within nursing research (Välimäki et al., 2007) but the rationale for their

inclusion in this study was as a means of capturing those who might be willing to participate in the study but who might not be willing to be involved in interviews. Alternatively, the diary could be used as a supplement to the interviews and as a way of keeping a record of their everyday experiences. Subsequently, it would act as a stimulus for discussion of daily living in subsequent conversations. Participants' preference for multiple, audio-taped interviews and/or diary keeping was established at the initial meeting.

As the meaning of living with chronic pancreatitis occurs in a social and cultural context, I sought permission from participants to include a close family member¹¹ of their choice in one of the conversational interviews or to undertake a separate interview in order to ascertain their perspective.

In order to keep my prejudices in view and facilitate reflection on the experiences of data collection and subsequent data analysis I maintained a journal throughout the study.

4.8.1 The Interview Process

Data collection was undertaken between September 2005 and March 2007 with interviewing, transcription and initial analysis occurring simultaneously.

4.8.1.1 Gaining consent

All patients who returned the expression of interest slip were contacted by telephone to arrange an initial meeting to discuss consent and participation in the study. At this point, five of the participants indicated that an initial meeting was not necessary and they would formalise the consent to participate in the study at the first interview. Meetings were arranged with the remainder at their convenience, the locations of which varied between their homes and public meeting places such as hotels. The purpose and nature of the research was reiterated and any questions or queries were answered. Guarantees regarding the confidentiality of the audio-tapes and the

¹¹ Those diagnosed with chronic pancreatitis were the primary participants in this study. However, family members were also deemed to be participants even though they could not enter the study except through a close relative who had received the diagnosis of chronic pancreatitis.

transcripts were offered and anonymity was assured through use of a numerical code. It was outlined that the names of people or places mentioned during the interviews would be anonymised during transcription. It was clarified also that members of the team managing their care would not know of their ultimate inclusion in the study. Two original consent forms (see Appendix 5) were signed and a copy retained by the researcher and the participant. The participant's right to withdraw from the study without question at any time was repeated. A time and date for the first formal interview was arranged. At the point of initial contact, thirteen of the fourteen participants indicated their preference for participating in audio-taped interviews alone with one only indicating that he wished to maintain a diary as well.

4.8.1.2 Preparing for interviews

Although a significant aspect of preparing for the interviews constituted the explication of my prejudices, I considered it necessary to prepare how I would 'be' in the interviews by identifying and being cognisant of strategies and processes that would facilitate the participants' explication of their living with chronic pancreatitis. In order to facilitate this, I followed the strategy recommended by Wengraf (2001) and designed an 'opening question' that was aimed at eliciting the participants' narrative. After considerable reflection, I determined that at the beginning of the first interview I would ask the participants to:

'tell me how you came to be diagnosed with chronic pancreatitis'.

Although this could be construed as prescriptive as it focussed immediately on the diagnosis of chronic pancreatitis, I anticipated that in the telling, the participants would situate it within the overall context of their lives. I planned that my participation in this section of the interview would be focussed on attending and active listening rather than asking questions, other than to encourage or elicit further narrative or ask for clarification. Through this strategy, I anticipated that the basis for subsequent more discursive dialogue would be established.

Although the length of each interview could not be pre-determined, a two hour period was allocated so that introductory and de-briefing phases could be incorporated (Warren et al., 2003). Since participants were from a wide geographical area, I had to ensure also that I allocated adequate time for travelling to and locating the chosen venue.

Ten of the participants chose their own home as the location for their interviews whilst the remaining four chose public locations such as local hotels or coffee shops. On one occasion, at the participant's request, his third interview was undertaken whilst he was hospitalised. Although giving the participants freedom to choose the venue was associated with benefits related to participant comfort, convenience and scheduling, I became aware that there were potential personal safety issues entering unfamiliar areas and strangers' homes. As advised by Basia (1996), I devised a strategy for action in the event that I did not make contact with a named person, by telephone, after a specified length of time. However, this was constrained by the overarching requirement to maintain participant confidentiality and I was unable to divulge the address to which I was going.

From a practical perspective, I decided, following previous experience with analogue recording using traditional cassettes, that a digital recorder would be less intrusive in the interview setting, would deliver enhanced sound quality and would be more efficient in terms of access, storage and archiving (Mitchell et al., 2004). Therefore, I chose an MP3 player with a 20 gigabyte hard drive so that there was no restriction on length of recording and all interviews could be stored on the system with back-up on a desk top computer. As a result transcribing was facilitated by the enhanced media facility on the computer.

4.8.1.3 The interviews

On the day before each scheduled interview, the participant was contacted by telephone to reconfirm the meeting. This was considered important given that they have a condition whose acuity can change in a short space of time. This resulted in rescheduling for a small number of the interviews. Prior to commencing the formal part of the interview, where applicable, written

consent to participate in the study was obtained or, in the case of the remaining participants and all subsequent interviews, consent was reconfirmed verbally.

The first interview

At the beginning of the process of undertaking interviews, I was acutely conscious of 'intruding' on these people's lives. This feeling remained throughout the first interviews despite the participants' apparent willingness to meet with me and talk about their experiences. On reflection, this was, in part, attributable to our status as 'strangers'. To counter this, I engaged in strategies at the greeting stage (Warren et al., 2003) that were aimed at minimising the formality of the occasion. I allowed time for the participants to get to know me and I willingly answered questions about myself and/or the research. One aspect of this rapport or social talk (Wengraf, 2001) that was particularly successful in 'breaking the ice' was associated with what I term 'county' or 'provincial' tribalism in Irish sport. This often resulted in joking and teasing about the success or failure of one's county or province and appeared to minimise any sense of inequality between 'professional researcher' and 'patient'. From the participants' perspective, offering tea or even lunch seemed an inherent part of welcoming me to their homes as their guest. This pre-interview ritual was an important part of the process regardless of whether the interview was taking place in their home or a public place. In some households, other family members were present and during natural breaks engaged in social talk but removed themselves for the formal part of the interview, which was marked by switching on the recording equipment.

Most participants appeared more at ease when I began to prepare the recording equipment. During this time I talked about the benefits of modern technology in relation to recording material and emphasised its unobtrusiveness.

I began the first interview with my planned question as outlined above and although this elicited an immediate response, many became more hesitant and often asked questions like; 'is this what you want?' or 'where do you want me to start?' In these instances, my responses were 'whatever you are willing

to tell me is OK' or 'start from wherever you feel you can best tell your story'. I constantly re-iterated my appreciation that they were willing to share their story with me. Kestin van den Hoonaard (2005) refers to this 'dance of orientation' as a means by which the participant is asking for clarification of the rules. The benefits of the initial meeting became apparent at this stage. Even though that meeting had not been audio-taped, in practice, the participants had begun to tell me their story, which I was able to recall thereby enabling me to direct them to pertinent starting points or issues.

When necessary, I did ask prompting or clarifying questions. This appeared to be confined, in the main, to areas where the participants were attempting to explicate how aspects of their lives had changed or altered. For example I asked;

'Why do you feel time has changed for you?'

'Are you saying you are more aware of your body?'

'Can you tell me how your relationship with your wife has altered?'

In general, the first interview focussed largely on the telling of their story and what it meant for their lives. On average, each recording lasted between one and one and a half hours although the time spent with the participant was often in excess of two hours. This was because the rituals engaged in before the interview, were frequently mirrored afterwards. To some extent, I likened these to social rules about disengaging and leave-taking. For example, where I was invited to have 'a cup of tea before you go', I had to determine if this was an indicator that they wanted to continue to talk or whether they were just being socially polite. In some instances, however, participants used the time after the interview to seek information or advice about chronic pancreatitis, the care and treatment they were receiving or even my opinion as to the quality of that care.

Second and subsequent interviews

I began the second and subsequent interviews, by asking participants how they had been in the intervening time since our previous meeting. In most instances, they responded by outlining how they were feeling physically and psychologically and any medical treatments or developments that had

occurred. In what constituted the second part of the interview the participants' response to the transcript was ascertained and any concerns or questions explored. The exploration of their responses to the previous interview comfortably initiated the discussion and in many cases, the questions and areas for clarification were answered without prompting.

In respect of content, many expressed surprise at the size of the document and verbalised a slight discomfort related to the number of colloquialisms they had used. For the most part, they indicated that they were satisfied that the transcripts represented what they had said. Two participants requested small portions of text be removed, which were related to disclosures they had made but had since regretted.

Second and subsequent interviews were highly discursive but differed in that their focus was a more of a question and answer dialogue than the 'telling' nature of the first interview. This was because I was consciously attempting to elucidate my preliminary understanding of their experiences, which I considered was important for moving towards the ideal of a 'correct' interpretation.

In the case of two participants it was mutually agreed at the end of the second interview that a third was not necessary. They indicated that they had felt they had told me their 'story'. However, it was emphasised that should they want or need to contact me about any aspect of their experiences that they could do so. One of them maintained contact for some months through occasional text messages. With the exception of Participant 13, a natural closure was achieved with the remaining participants at the end of the third interview. This was identified as a perception that the participants had nothing 'new' to offer and that the researcher had nothing 'new' to ask. Transcripts were returned to participants following their third interview and it was stipulated that further contact by the participant was not precluded. I also requested permission to contact them during the analysis phase of the study should I need to. This was readily forthcoming.

Following each interview the audio-tapes were personally transcribed during which they were cleaned of any personal identifiers such as the names of people or hospitals, and a letter and numerical code was attached to each. Over the period of data collection, two recordings failed. While one was eventually recovered, the other was lost. In this instance, extensive field notes were made based on my memory of the content of the interview. This was revisited with the participant at the next interview. A coded copy of the transcript was returned to each participant prior to the next interview. The schedule of interviews was tracked on an excel spreadsheet to ensure adequate time was allowed for transcription, the return of the transcripts and their viewing by the participants prior to the subsequent meeting. Each participant was contacted by telephone to inform them that the transcripts were being returned. They were contacted again approximately one week later to arrange the next interview. At this point, several of the participants began to communicate via text messaging. They used this process to inform me that transcripts had arrived and that they were satisfied with what they had said. Two participants used text messaging to inform me they had been admitted to hospital and another communicated the results of her visit with the consultant. The text of these messages was also transcribed and tagged to the participant.

4.8.1.4 Analysis during the interview process

Between the interviews, an initial analysis of the transcript was undertaken, which involved reading and re-reading whilst listening to the recordings. This facilitated the beginnings of understanding as it enabled me to start to examine what was said but also what was not said. Wengraf (2001) argues that embedded in narrative are clues to the social, cultural and personal reality of the participants. By encouraging narration, the participants not only described their lives but also explicated their understanding and offered possible interpretation and meaning.

From a practical perspective this process also allowed me to identify speech that was not clear or where there were aspects that needed further clarification or development. Subsequently, notes and memos were entered in the transcript margins and questions prepared for subsequent conversations.

4.8.2 Diary-keeping

Participants were also offered the opportunity to keep a diary, for a six-month period, of their everyday experiences of living with chronic pancreatitis, which had the potential to provide different insights. However, only one participant indicated that he wished to do so. Following his first interview, a blank notebook with pull-out pages was supplied. It was specified on the inside cover of the notebook that the nature, content and length of entries was not prescribed but could include descriptions of what he considered a 'good day', a 'bad day' or a 'typical day'. It could also include how he was feeling physically and/or psychologically and could outline any activities or social engagements he may have been involved in.

At his second and third interviews, he gave me the diary entries, which I subsequently transcribed, returning both the original and transcribed entries to him. Any identifying features were removed from the transcript and a letter code applied. Following his third interview he indicated that he wished to continue using the diary, which he did for a further three months, at the end of which a fourth and final interview was undertaken where he indicated he had nothing new to tell me.

4.8.3 Interviews with family members

Four participants indicated that they wished a family member to be included in the interview process. For one, his wife was involved in all three of his interviews with his daughter also taking part in one. Another participant's wife took part in his first interview. Of the remaining two, one indicated that his mother wished to be interviewed and the other identified his sister as being willing to be included. The former of these lived abroad so it was necessary to set up a telephone interview whilst the latter was undertaken in her home. Information was provided (see Appendix 6) and written consent was obtained from each family member (see Appendix 7). For the participant's mother who lived abroad, consent was obtained by email.

Transcripts from joint interviews were managed in the same way as individual interviews. The telephone interview was transcribed and sent by email for clarification, which was duly received, also by email.

A total of 41 individual or joint interviews were undertaken, 39 of which involved the person who had a diagnosis of chronic pancreatitis. The remaining two interviews were with close family member interviews undertaken independently of the primary participant. Participant Number 12 partook in one interview but did not attend for the second as arranged. The data from her interview has been included as, during a telephone conversation prior to the planned second interview, she indicated her satisfaction with the transcript. Participants' involvement in the process ranged from three to five months with approximately four to six weeks between each interview.

Throughout the data collection period I was concerned about achieving saturation on two levels. Overall, I was anxious about deciding when to stop recruiting to the study. Originally, it was anticipated that in the region of 20 participants would be a realistic number. The final decision to stop at 14 patients was mediated by the quality and amount of data generated and the sense that further data collection would not necessarily enhance this. At this point, I had gathered 56 hours of recorded interview data and there appeared to be no new or different concepts emerging.

In respect of saturation at the level of each participant, I was aware that understanding is never static and the process of interviewing, analysis, returning to the participants, gaining new understandings and re-entering the hermeneutic circle could go on indefinitely. Although the closure on formal interviewing appeared to occur naturally and was collaborative, I believe this was facilitated by my conscious awareness of balancing my need for exhaustive data without imposing on participants who were willing to tell their story but who were essentially vulnerable.

4.8.4 Reflection on the interview process

As indicated above, I maintained a journal throughout the preparation and implementation of data collection. In addition to my pre-understandings regarding what it means to live with chronic pancreatitis, following each interview, notes and entries were made in respect of my overall perception of the interview, my own performance as an interviewer, how I felt my pre-understandings impacted on the interview and my initial thoughts and interpretations about what the participants were telling me. The following reflections outline some of what I consider to be key issues that emerged during the process of data collection. Others are presented in the section on ethical integrity.

My conversations with the participants raised some questions about issues I explored with some and not with others. For example, I found I could not bring myself to ask some of the men in the study about the impact of living with chronic pancreatitis on their sexual and intimate relationships with their partners/wives. The issue had been raised originally by one woman and thereafter became part of my emergent understanding. Therefore, I hoped to be able to pursue it with others. Reflecting on my reluctance, three reasons emerged. Primarily I believe it was associated with my own perception of what might be considered intrusive. Secondly, I noted I was more comfortable asking the question of women, which I judged may be a reflection of my own prejudice about the willingness of men to discuss their private and personal lives. Thirdly, I questioned my skills and ability to facilitate such discussion. If the participants understood the couched terms with which I phrased the question and volunteered the information I was satisfied. If they did not I tended not to pursue it any further. Whilst initially this seemed like an inadequate strategy, I finally concluded that I would have to accept that participants would tell me only what they were willing to divulge. Moreover, though I considered this an area of value in people's lives, I became aware that they, the participants, may not consider it a priority in their overall illness experiences.

In respect of engaging with participants, I noticed, whilst listening to the tapes and reading the transcripts that sometimes I referred to others'

experiences when framing a question or making an observation. I began to consider why I did this as it was never planned in advance. On reflection, I seemed to use it as a strategy to justify asking a particular question and secondly offered it as a kind of covert reassurance to the participants that they were not 'alone' in their experiences. The need to provide this reassurance seemed to originate in my interpretation of some of the verbal and non-verbal responses of the participants and in some cases their 'not knowing' about the condition. Whether this was an accurate interpretation cannot ever be truly known.

An attendant worry, however, was that I might be 'leading' the participants and unconsciously looking for patterns to strengthen the 'evidence' for my final conclusions. Two issues emerged from my subsequent deliberations. Firstly, Fleming et al (2003) outline how, in Gadamerian hermeneutics, understanding of the subject matter and the understanding of the researcher changes over time. Changing pre-understandings, as referred to previously, influence each dialogue with a participant. Therefore, it must be assumed that if data collection is being undertaken with several participants simultaneously the influences cannot be confined to each individual but are also between and across individuals. As a result, I believe my questions and observations were also attempts to verify my understanding of the subject matter and were a reflection of my emerging or changing understanding.

4.9 Data Analysis

The hermeneutic task in this study was to translate the participants' experiences into a construction of the meaning of living with chronic pancreatitis. Although Gadamer did not identify a process for constructing meaning, his principles of 'application' and 'fusion of horizons' were fundamental. However, the data analysis process presented here as essentially linear and discrete, belies the complexity of applying these principles. It was my conception that the process was, in effect, a moral task of striving for the best possible representation. Thus, it was marked by a pervasive uncertainty that led to continuous questioning. Analysis became an iterative process of constant re-reading of the texts, reflecting on their perceived meanings, revising and re-writing emerging interpretations and

engaging with the literature in the struggle to find the words that best represented the meaning.

Analysis was undertaken during the interview process for the purpose of identifying aspects of the transcripts that needed further elucidation and for clarifying emerging understandings and correcting possible misunderstandings. At the end of data collection, formal analysis of all the 'texts' began with a consideration of how the process would be undertaken.

4.9.1 Preparing for data analysis

Several factors needed to be taken into consideration when choosing a method for undertaking analysis. In the Gadamerian sense, 'texts' were complex and included the interview transcripts, diary entries, the recorded words, text messages, written comments and my reflections and observations about the interviews.

In addition, I had to consider how my pre-understandings and changing horizons could be integrated in order to demonstrate how I entered the hermeneutic circle of interpretation and a judgement made as to whether or not I had remained orientated to the subject of the study. Although the final interpretation would be my ultimate responsibility, I hoped to show how it had emerged from a shared understanding between me and the participants. Yet this shared understanding is constructed in the dyad of the researcher and participant and in the context in which it occurred and is therefore temporal. Hence, it would be difficult to utilise an approach that demanded 'expert' or 'peer' verification since another person may not be able to reach the same understanding.

Furthermore, even within the dyad, the horizons of the participant and the researcher change and move and context and situations alter. This was important for me since during data collection I came to recognise how each participant's living with chronic pancreatitis was fluid. As a result I had to come to an acceptance that our shared understanding and my final interpretation would be applicable to moments of their overall living and would not be forever. Ultimately then, as the interpreter of the data I had to

be flexible and able to tolerate inconsistency and possible uncertainty related to my understanding. What was important was that I would choose an approach that was flexible enough to illustrate this in sufficient detail so that others could 'understand' my understanding.

Although the complexity of the texts precluded an approach to data analysis that would focus only on the 'text' of the participants, my belief was that this very complexity necessitated a systematic and consistent method. Yet, I was conscious that hermeneutics does not have a tradition of a staged approach to analysis (Clarke, 1999).

Support for my view that the process of gaining understanding needed to be systematic was found in the work of Fleming et al (2003) who proposed a cycle of four steps (Figure 4.1) that facilitated the hermeneutic rule of movement from the whole to the parts and back to the whole. However, an inherent flexibility is retained when they emphasise that each step is not mutually exclusive and may occur out of sequence or simultaneously. Therefore, whilst not being overly prescriptive in the staging of the analysis it provided me with a framework that would enable manifestation of the essential meaning of the whole text as well as a detailed understanding of the phenomenon being studied. Furthermore, the cycle of four steps was developed with particular reference to the philosophical foundations of Gadamerian hermeneutics, a factor I considered important for methodological coherence.

Having decided on the process for data analysis, a more practical consideration concerned how I would 'manage' the large volume of data. To this end I explored the availability of computer software programmes that would accommodate storage and management. The choice of NVivo Version 7 (QSR, 2007) was bound in its ability to allow me to code the texts inductively and provide a permanent record of my decision-making throughout the analysis process. Nonetheless, I was conscious that the construction of relationships between codes and themes and the development of possible models was a cognitive process that might necessitate supplementation with manual conceptual mapping.

In keeping with the Gadamerian view that all sources of data are considered 'texts' for the purposes of achieving understanding, the individual participant and family member interviews, joint interviews and diary entries were imported into the data management system and stored as individual sources. Although the diary entries constituted data in a different *form*, they had been a focus for discussion in the participant's interviews and offered important supplementary information in respect of his everyday living. Therefore, although held as an individual source, they were tagged to the individual participant. Joint interviews were stored as an individual source but an additional file was also created where the primary participant and family member's contributions were separated. Although this was an entirely false separation and ultimately of little real value, at this point, I considered that it might facilitate coding of family members' experiences.

Figure 4.1: Steps of Data Analysis

STEP 1 – Gaining understanding of the whole text

examination of the interview texts to gain an understanding of the whole

STEP 2 – Detailed analysis of text

detailed investigation of text to expose its meaning for understanding of the subject matter and the identification of themes

STEP 3 – Expansion of the unity of the understood sense

relating the detailed examination of the text in Step 2 back to the whole thus expanding its meaning

STEP 4 – Representing shared understandings

identification of passages that seem to represent the shared understandings between the researcher and participants

(Fleming et al., 2003)

4.9.2 Step 1 – Gaining understanding of the whole text

I initiated analysis by simultaneously reading the transcripts and listening to the audio recordings of the first participant. By repeating the process on several occasions I achieved a level of immersion where I found I was not only able to recall each of our dialogues clearly but also the interview environment and my feelings and emotions associated with each. Clarification

of my emotional and cognitive responses was undertaken by referring to my reflective journal entries.

At this point it was my intention to begin a detailed examination of the interview texts of this participant as described in Step 2. As I began this process using NVivo Version 7, I experienced a discomfort associated with the idea that I would lose the sense of the whole whilst examining the parts. This was based on my belief that as I progressed through the process with each participant the cognitive complexity of attempting to retain a sense of the whole of each participant's living with chronic pancreatitis would be overwhelming. I also felt I would not only have to return to Step 1 but would have to undertake it again once Step 2 was complete. Whilst this would be acceptable given the flexibility of the approach I also realised that the integration of multiple texts would not have been explicated. Therefore I began to contemplate on how best to elucidate Step 1 of the process.

Having reflected on what I was trying to achieve, I experienced a further discomfort associated with the possibility that I was now omitting parts of the 'process' of analysis and focussing on outcome. Finally, I found support for this approach in the work of Clarke (1999:365) where she states, that proper entry into the hermeneutic circle is 'enhanced through writing the story in one's own words as it encourages a deeper engagement with the participant's story'. Furthermore, it facilitates gaining a sense of the whole, can include the researcher's reflections and is seen as enabling further recognition of one's own prejudices (Clarke, 1999). I also anticipated that writing the story in such a way would facilitate Step 3 of the process of analysis.

Therefore, I decided to write each participant's story first using all 'texts'. Although it detracts from the story to a certain extent, contextual issues and identifiable characteristics of the participants were omitted in the writing for the purpose of ensuring continued anonymity. The written stories are structured as follows:

a) Interviews and Reflection

- This section included the context, number and timing of the interviews as well as my reflections on the experience.

b) The Story

- The Beginning
- Living with Chronic Pancreatitis
- The Future

Where a family member had been interviewed their story was structured using the same format but without the sub-headings in 'b'. These were attached to the primary participant's story.

The process of writing the stories was protracted as I sought to represent them accurately in my words. Although writing a story in one's own words includes an element of interpretation, primarily, this was the participants' description of their living with chronic pancreatitis. I constantly confirmed and re-affirmed my descriptions by returning to the original data sources, which in turn facilitated deeper immersion as did my motivation not to misrepresent the participants.

Writing my reflections on the context and process of my interaction with each participant was facilitated by entries in my reflective journal and the ease with which I could recall each event. The final outcome was 14 stories that facilitated re-entry to the texts (see Appendix 8 for examples).

4.9.3 Step 2 – Detailed analysis of text

Having written the participants' stories I began the second stage of analysis by returning to NVivo Version 7 with the purpose of undertaking detailed analysis of each interview. I decided that I would not refer to the constructed 'stories' during this stage as I believed the subsequent themes would enable a measure of verification between the outcomes of Steps 1 and 2.

All interviews for each participant were analysed before progressing to the next participant. Where joint interviews were undertaken, I returned to the

texts to undertake analysis with the view to identifying themes that were pertinent to the family member's living with chronic pancreatitis.

Throughout this stage of analysis I kept the hard copies of each participant's interviews near at hand. This was partly due to my lack of familiarity with navigating the NVivo system and my initial difficulty locating sections of text on the computer-held copy as well as a sense of being unable to contextualise on the computer screen.

4.9.3.1 Coding

As the process was primarily inductive, the initial labelling of codes was difficult. I found I could not limit the unit of analysis to a word or sentence as a participant's focus or meaning could often only be determined by including the surrounding text. Furthermore, as part of remaining 'true' to the participant's texts, I had not created 'a priori' codes. As a result, considerable time was spent trying to create nodes (codes) to represent what the participants were saying. In many instances, these sentences and their surrounding text were coded in more than one place.

This beginning stage appeared very protracted and I became frustrated with my perceived lack of ability to represent adequately what was being said and with the slow progress being made. I then realised that elements of this frustration were associated with my interpretation of the structure of the NVivo system. Two main types of nodes (codes) are utilised: 'tree' nodes and 'free' nodes. As the name suggests, the former are organised into a hierarchical structure moving from a general category (parent node) to more specific categories (child nodes). Conversely a 'free node' is a stand-alone code that does not have an obvious connection to other nodes. I recognised, at this point, that I was attempting to construct the hierarchy as I was undertaking the analysis with a resulting frustration when sections of text did not appear to 'fit'. Although at this point I had created several tree nodes with associated 'child' nodes, I decided to simplify the process by focussing exclusively on labelling with the intention of returning later to refine the structure. As a result, most of the codes subsequently created were 'free'

nodes. (Examples of the early Tree and Free Nodes can be found in Appendix 9).

As to be expected, most codes were created during analysis of the first five participants' transcripts with fewer new codes emerging in the latter stages. Coding of the first interview transcripts with each participant was more time consuming and complex than second or subsequent texts. This seemed to be because the latter appeared to be a continuation of the first encounter and many of the codes created during first interview analysis were applicable. Furthermore, textual analysis of the first interview involved re-entering the data with a different participant whose use of language, nuance and methods of describing issues varied. Therefore, the cognitive processes and labelling of intended meaning was always more protracted.

However, increasing familiarity with the available features of the NVivo system facilitated a level of consistency as the analysis progressed. The system facilitates coding sections of text in more than one place. Therefore, where I was unsure of how to code a particular section of text or where more than one issue was being addressed and to attempt to separate them would have decontextualised or caused a blurring, I was able to label them accordingly. 'Coding stripes' on the system enable the coding for that particular section of text to be viewed in the transcript (source) or at a particular code (node).

At times, when analysing sections of text I would recall that another participant would have made the same or a similar point yet I would be unable to remember how I had coded it. In these instances I used several strategies to locate the text. In the initial stages I would examine the Tree or Free nodes for the source reference I needed. However, as the analysis progressed this strategy proved inefficient due to the sheer number of nodes. In some instances I used the 'queries' facility, which enables the researcher to enter a text query. However, this feature highlighted all sources or references to the search term and proved time consuming. The most efficient strategy proved to be the 'find text' feature. When the desired section of text was located I highlighted the attached coding stripes. However, a limitation of all

of these features was the need to remember a word in order to begin the search process. Although the ability to remember who had made the point and the word used was an indication of my familiarity with each of the texts, it was at times frustrating when the required text was not easily located.

4.9.3.2 Annotations

In the later parts of this phase of analysis the 'annotation' and 'memo' features of NVivo proved useful. Annotations are similar to notes made in the margins of transcripts when undertaking manual analysis. By highlighting the section of text under consideration, an annotation is inserted that can be viewed at any time. Importantly, the text remains highlighted to prompt the analyst that a comment has been made. Annotations attached to participants' talk included clarifying comments about the context, questions about possible meaning, uncertainty on my part about the coding of the item and in some instances my reaction to what was being said. Annotations to my talk included what I considered to be evidence of my changing horizons and my responses to what I perceived was happening in the interview at that moment (Table 4.1).

Table 4.1: Examples of Annotations

Annotations
<p>Annotation on the node 'monitoring'</p> <p>Monitoring incorporates all of the observing and indicating changes since the onset of illness. Monitoring here is about weight but there may ultimately be a code about Changing Physical Self. Observing is also a code that needs to be incorporated.</p>
<p>Annotation on a section of text</p> <p>Here the patient was asking for my advice about his apparent dissatisfaction with his GP. He did not know how to seek the help he perceived he required. It was difficult to give advice without appearing to be directive/prescriptive.</p>

4.9.3.3 Memos

Although memos are seen in NVivo as a type of source that can be imported in a manner similar to other documents, my use of them was confined to thoughts, views and processes related to the coding process. For example,

each memo is directly related to a Tree or Free node. In the memo, I made descriptive and interpretive comments concerning the meaning of the code as well as possible relationships with other codes. Similarly, where distinctions between two codes were blurred, I noted this and made suggestions for possible re-labelling or creating new codes (Table 4.2).

Table 4.2: Examples of Memos

Node	Memo
Embodied Past and Life Before Chronic Pancreatitis	<p>This code is linked with life before chronic pancreatitis - I just have to be sure that I clearly differentiate them if there is a need to. Some parts of the text are coded in both but check as not all are.</p> <p>Life before chronic pancreatitis is, I think, about behaviour, habits, ways of conducting their lives. Social milieu is about values, families, where they were born, etc.</p> <p>Embodied past is very similar to social milieu and they may be incorporated together.</p>
Enduring restrictions	<p>Enduring in the sense here has two meanings. There is enduring the restrictions or putting up with them but also about restrictions that endure on a continual basis.</p>
Financial constraints	<p>A broader view of financial constraints is needed here. I think the constraints of the social welfare system need to be included in this section. I have some coded under Professional Support - they need to be moved as well as those under Managing the Health Care System - these need to be grouped together.</p>

4.9.3.4 Conceptual mapping

During this phase of analysis, 11 Tree nodes with 53 Child nodes and 80 Free nodes were created. In addition a separate tree node with 14 child nodes was created to describe family members' living with chronic pancreatitis.

The process of coding was essentially an extended one that required persistence and cognitive application whilst tolerating uncertainty regarding the accuracy of my labelling. I recognised through the use of memos that some of the codes were either labelled incorrectly or were positioned incorrectly in the hierarchy of nodes. However, in order to complete the process I continued with the coding whilst acknowledging that refinement would be necessary.

I also began to experience uneasiness about how I was going to relate or link the increasing number of codes. Although the linear process of coding was an essential requisite for the subsequent stages, it triggered thoughts of how the parts could be related back to the whole, differentiated in Figure 4.1 as Step 3. This, I believe is reflective of the iterative nature of qualitative data analysis and indicative of the need to tolerate the fluidity of the process. In order to address these thoughts, I began to undertake conceptual mapping manually. In this way, I began to group codes together under as yet unlabelled themes. Thus, I was able to complete the coding process whilst at the same time taking cognisance of my deliberations for Step 3.

On completion of the initial coding, I returned to my previously created conceptual maps. Together with a printed list of the Tree and Free nodes, I began to re-structure my initial mapping in an attempt to represent the themes and codes logically. Through a process of deliberation, detailed examination and revision the organisation of the themes and codes became more coherent. However, it also became evident that refinement of the initial coding was necessary.

At this point I returned to the data management system to re-organise the themes and codes into a system that reflected the emerging structure. This necessitated examining each code individually to not only check the original coding but restructure the content and hierarchy. Since the initial coding had been undertaken over a period of two months, the process of revisiting also acted as a verification procedure.

The final arrangement of codes and themes at this stage of the analysis included 15 Tree Nodes, 14 of which were concerned with the Participants' experiences of living with chronic pancreatitis. The remaining Tree Node was related to family members' living with chronic pancreatitis (Table 4.3). Each Tree Node represented a significant theme arising from the data. Within each of the Tree Nodes there was a varying number of Child Nodes which represented the constitutive codes (Table 4.4) In addition, there were 8 Free Nodes or codes that were not linked directly to any of the Tree Nodes (Table 4.5)

Table 4.3: Family members 'living' with chronic pancreatitis

Tree Node (Theme)	Child Nodes (Codes)
Family members 'living' with chronic pancreatitis	Altered person in illness Being afraid Being protected from Coming to know Conflicting views Emotional distress for Hoping for Intervening or acting for Monitoring Persuading Seeking explanations Supporting Uncertain future Validating

Table 4.4: Living with chronic pancreatitis – Thematic structure/hierarchy

Tree Nodes (Themes)	Child Nodes (Codes)
Altered economic circumstances	Containing financial demands Occupational disruption Financial vulnerability/constraints Managing health care costs
Altered self in illness	Disturbed normal Being afraid Fear of complications Fear of future Fear of pain Being angry Feeling down Loss Loss of coherence Loss of confidence Loss of control Loss of healthy self Unacceptable losses Worry
Altered social relationships	Others' perceptions of illness Social isolation & withdrawal

Tree Nodes (Themes)	Child Nodes (Codes)
Coming to know	Being diagnosed Explaining Attributing Paralleling 'Finding out' Being informed Conflicting information Sourcing 'Unknowing' Onset of physiological disruption Path to diagnosis
Emotional coping	Adjusting expectations Avoidance Distraction Faith Hoping Limits of suffering Normalisation Paralleling Resilience Seeking control Trade-offs
Interacting with healthcare professionals	Perceived limits of medicine Perceived value of professional consultations Relating to healthcare professionals Being 'believed' Being judged Being validated Convincing healthcare professionals Disclosing 'Having faith in' Informing Lay vs professional knowledge Significance of interactions with healthcare professionals Being monitored Being treated Efficacious treatment Enduring treatment Inefficacious treatment Knowing the healthcare professional Nature of interactions with healthcare professionals Perception of expertise Professional accountability
Negotiating the welfare maze	Eligibility Gaining entry Resolution

Tree Nodes (Themes)	Child Nodes (Codes)
'New' normal	Accepting limitations Enduring restrictions Immersion in illness Behaviour in illness 'Slowed' time Uncertain body Uncertain future Unpredictable 'norm' Bad days Good days Unsustainable 'old' normal
Personal relationships	Altered personal relationships Conflict 'in' Sustaining
Redefining 'self'	Emotional connectedness Transforming experience
Seeking health care help	Negotiating the health care system Frustrating systems Gaining entry Waiting Other sources of help Seeking professional help
Self-management	Self-care Handling the pain Modifying lifestyle Prioritising demands Struggling to live well Self-monitoring
Social resources	Family support Friends' support Other support Non-professional support Professional support
Unpredictable daily disruptions	Complicating pathologies Inability to eat Gastrointestinal disturbances/food intolerance Iatrogenic effects Incapacitating fatigue Interrupted sleep Intrusive pain Loss of physical strength Unexplainable symptoms

Table 4.5: Free Nodes

Free Nodes
Defining 'me'
Disruptive hospitalisation
Embodied past
Life before chronic pancreatitis
Personal values
Salient physiological disruption
Social influences
Social Milieu

4.9.4 Step 3 – Expansion of the unity of the understood sense

Although the exhaustive and detailed examination of the texts led to identification of codes and themes and expanded understanding of the participants' stories as outlined in Step 1, they could not be said to denote the meaning of living with chronic pancreatitis nor did they represent the fusion of the participants' and my horizons. Furthermore, the inter-relatedness between the themes and codes was not evident as they were not integrated or organised conceptually. Because of this I believed they did not capture the fluid and ever-changing nature of 'living' with chronic pancreatitis.

I found this part of the process challenging because I was anxious about misrepresenting the data. Yet, I began to believe that the conceptualisation of living with chronic pancreatitis would be best achieved through creative engagement with the texts. I felt that in order to construct an understanding, I needed to identify major unifying categories that linked the themes and codes.

At this point, all texts including the conceptual maps, the themes and codes, and the participants' stories created at Step 1 were examined together with the intention of generating major unifying categories and constructing a higher level conceptual representation of living with chronic pancreatitis. This was a search for or seeking of that which unified or fused all sources of data. An important insight at this time was that the texts were inseparable. For example, I made the decision to integrate the 'family members 'living' with

chronic pancreatitis theme' and its constituent codes with the remaining themes and codes because it was a part of the whole of living with chronic pancreatitis.

The process of generating unifying categories involved returning again and again to the data sources whilst constructing and re-constructing the representation. Finally, after prolonged engagement it emerged through logical deduction and intuiting meaning that participants spoke of a life disrupted. This notion of disruption had emerged early in the analysis but in my anxiety about misrepresenting the data and rigidly adhering to the process I had consciously quelled this instinctive conceptualisation. The concept of 'enduring' subsequently emerged during my deliberations on the permanency of the disruption to their lives. Linked to this however, was the idea that enduring was also about tolerating or coping with the disruption. Thus, I came to represent my early understanding of the meaning of 'living with chronic pancreatitis' as 'enduring disruption'.

'Enduring' as it is represented in this study has a two-fold meaning. Primarily, it is an adjective to describe the perpetual or permanent nature of the disruption and occurs at physiological, social and psychological levels that constitute its three unifying categories. Secondly, it is a verb 'to endure' that is, 'to cope with' and/or 'to tolerate'. In this sense, enduring refers mainly to how the participants and their families cope with the perceived restrictions arising from the condition, their capacity to tolerate them and the strategies developed to manage them.

Participants pinpointed the catalyst for their disrupted lives as the day they received the diagnosis of chronic pancreatitis. Despite experiencing prior physiological disruption, with diagnosis came a realisation that their lives were irreparably changed. The marker for evaluating the extent of that change and the perception of their quality of life is life before chronic pancreatitis. Coming to know the disruption of chronic pancreatitis includes coming to know the condition, knowing the disrupted body, knowing how to manage and knowing what works. Through knowing, adaptations and adjustments are made. Living with chronic pancreatitis is characterised by unpredictable daily disruptions

interspersed with escalating or salient disruptions. Enduring unpredictable disruption generates a sense of a disturbed normal and a pervasive uncertainty about their future potential life.

This higher level conceptualisation enabled integration of the themes and codes through the three unifying categories of enduring physiological disruption, enduring psychological disruption and enduring social disruption. The two-fold meaning of enduring accommodated the diverse meanings embedded in the themes and codes yet it also captured the overall sense of the participants', and their families', living.

For me, this process marked the beginning of Step 3 of the data analysis process where the detailed examination of the text in Step 2 is related back to the whole thus expanding its meaning (Fleming et al., 2003). The final stage of this process is explication of the expanded meaning, which is presented in the following two chapters. Interpretation and gaining understanding was ongoing throughout and was facilitated by reference to pertinent and indicative literature. My ever-changing and expanding horizon was evidenced by the further revision and refinement of the themes and codes. It is proposed in Chapter 5 that the three unifying categories of enduring physiological disruption, enduring social disruption and enduring psychological disruption that symbolise enduring (permanent or perpetual) disruption represents 'suffering'. Subsequently, in Chapter 6, the second meaning of 'endure', 'to cope with' and/or 'to tolerate' expounds how the participants and their families 'come to know', and 'adjust/manage' through the development of self-management strategies within the overall process of transition from 'well' person to a person who lives with chronic pancreatitis. Together these form the whole of the meaning of living with chronic pancreatitis.

4.9.5 Step 4 – Representing shared understandings

Step 4 of the data analysis process involves identification of passages that seem to represent the shared understandings between the researcher and participants. In order to accommodate this, each of the following two chapters includes excerpts from the raw data that represent the aspect of living with chronic pancreatitis that is being discussed. However, I would contend that

any separation between expanding the whole and representing shared understandings is a false one and these steps are, in reality, indivisible.

4.10 Ethical Integrity

All research that involves human beings as sources of data has ethical and legal implications, which can be encapsulated in the right not to be harmed, the right to full disclosure, the right to self-determination and the right to privacy and anonymity. These over-arching rights are synthesised from the ethical principles of beneficence, non-maleficence, fidelity, justice, veracity and confidentiality as outlined by the International Council of Nurses (2003).

However, given the nature of qualitative research and particularly the use of direct interaction, such as the interviews used in this study, the ethical considerations and application of these rights is complex and changeable. Whilst a researcher can and must design an ethical protocol before the commencement of the study, in the implementation, additional unanticipated issues may arise. Therefore, the conduct of a moral study in qualitative research necessitates ongoing attention to ethical issues and dilemmas that may arise at any stage of the research process (Aita and Richer, 2005). Hence, I have taken ethical issues and considerations to be synonymous with ethical integrity. Ethical integrity not only incorporates elucidation of the procedures adopted to ensure an ethically sound research study, but includes reflection on ethical 'moments' or dilemmas that arose in the conduct of the research that have been described as 'ethics in practice' (Guillemin and Gillam, 2004; Guillemin and Heggen, 2008).

4.10.1 *Right not to be harmed*

Ensuring the overall right of the participants in any study to be protected from harm is the primary purpose of research ethics committees. Normally, as a doctoral student of the university, it was a requirement that institutional approval be obtained from the Faculty of Health Sciences Research Ethics Committee and the Local Research Ethics Committee of the hospital from which the participants would be drawn. However, because, in this instance the hospital is a teaching hospital under the auspices of the Faculty of Health

Sciences of the university and the participants were 'patients' of that hospital, institutional approval from its ethics committee encompassed both. Nonetheless, as a further safeguard, I was required to submit an application and meet with the School of Nursing and Midwifery Ethics Advisory committee to seek permission to proceed to the hospital research ethics committee. The purpose of the meeting was to clarify issues and answer questions the members had about the study. As a result of this meeting, some adjustments were made that enhanced the ethical reliability of the proposed study (see Appendix 10). Permission to proceed to ethical approval was granted by email from the committee Chairperson (see Appendix 11).

4.10.1.1 Vulnerability

In this study, the obligation to do no harm is encapsulated in the concept of vulnerability. Although the concept is poorly defined and in research ethics often focussed on intrinsic factors such as mental illness or learning disability (Smith, 2008), I would contend that by virtue of being a patient, a person is rendered vulnerable as there is the possibility that they are in a dependent and therefore unequal power relationship with their healthcare provider. At the outset, even though the gatekeeper was a member of the team caring for the patients, I guaranteed in the Information Sheet that their ultimate inclusion in the study would not be known since the 'expression of interest' slips were returned to the gatekeeper in a sealed envelope, which were then forwarded to me unopened. However, as the recruitment phase progressed, I realised that even though I considered the clinical nurse specialist to be the most appropriate gatekeeper in terms of protecting the patients there was also the potential that, despite assurances to the contrary, this study was one where the patients might perceive that what they said or how they lived would become known. For example, I presumed the fear that it would become known to their medical team that they continued to consume alcohol was a factor for some who chose not to respond to the invitation to participate in the study. Although this is conjecture, I came to believe that the decision to use the data controller as a gatekeeper and to approach participants directly through letter without recourse to a member of the medical/nursing team offered more protection. It had the added benefit also of ensuring that

patients were not approached while they were inpatients and therefore physically vulnerable.

I also considered the participants to be vulnerable because of the potential for the acuity of their condition to change suddenly. Having committed to participating in the study, I was concerned that they would agree to engage in an interview even though they were unwell. Parahoo (2006) echoes this when he suggests that people often feel obliged to 'help' having agreed to participate in a study. Although I realised that this was the participant's decision ultimately, I ensured throughout that they were given the opportunity to postpone or curtail any interview. As indicated earlier, I contacted all participants prior to their interviews and whilst engaging in dialogue I attended to indications that they were physically uncomfortable or becoming tired. I constantly checked with them that they were willing to continue.

Vulnerability has also been raised in the literature in reference to the relationship between the researcher and the participants (Orb et al., 2001; Aita and Richer, 2005). Qualitative research depends to a large degree on establishing good interpersonal relationships that enables sharing of rich data (Guillemin and Heggen, 2008). However, according to Guillemin and Gillam (2004), there is a fine ethical balance between building sufficient trust to facilitate disclosure and maintaining enough distance to preserve respect for the person. Central to achieving this balance is recognising the autonomy of the person and that what is shared is done willingly without coercion or deception (Orb et al., 2001). In this, Kvale (1996) refers to the subtle yet dangerous coercion or manipulation associated with quasi-therapeutic relationships that serve as a 'trojan horse' to get behind the defences of the participants and may result in disclosure of private lives and information that may be regretted later.

Furthermore, he argues that despite claims to the contrary, the interview is not comprised of egalitarian partners, and a hierarchical and therefore unequal power relationship exists between the interviewer and the interviewee (Kvale, 2006). Those who participate in qualitative research rarely

initiate or seek it and while there may be benefits these are not aimed solely at the participants (Guillemin and Gillam, 2004). Furthermore, the researcher is the one who identifies the subject matter, seeks the conversation and has a vested interest in gathering the data (Kvale, 2006).

These issues were significant in how I subsequently engaged with the participants in the study. As the essential instrument of data collection, my performance in the interviews was fundamental as was my honesty and integrity. Despite Kvale's (1996) warnings, I believed that I had to engage in strategies that would facilitate trust and disclosure. Nonetheless, I was mindful of attending to any actions or words on my part that could be construed as manipulative. Furthermore, I focussed on mutual collaboration in the interviews and as my relationships with the participants developed I strived to keep the conversations balanced rather than directive. In order to counteract what Dickson-Swift et al (2006) refer to as the naturally occurring hierarchy, I attempted to create a level playing field by engaging in appropriate self-disclosure about myself and my work and I did not avoid answering questions. In addition, I was honest about the outcome of the study in that I could not guarantee if the findings would result in any benefits for their healthcare management or provision of services.

Despite my intentions I was aware that the potential for inadvertent private disclosures remained. This consequence of rapport building has been referred to as boundary management and boundary slurring (Dickson-Swift et al., 2006). In the event, some participants did refer to personal aspects of their lives and although they could not retract what had been said, by providing them with the transcripts of their interviews, I afforded them the opportunity to have the hard copy record edited.

I was also mindful that participants' experiences and the process of recalling them might cause them to become distressed. Although I could not anticipate their exact nature, I recognised the potential for a blurring of the boundary between in-depth interviews and therapy referred to above as quasi-therapeutic relationships (Kvale, 1996). Therefore, I remained conscious throughout the interviews of the need to resist the temptation to offer

solutions or suggest interpretations that might jeopardise the participants' self-understanding or emotional well-being. I was aware that my role was not one of intervention as I was not a counsellor. Nevertheless, I had to consider how I would react to these emotions.

Ultimately I realised that I could not prepare universal strategies but had to gauge each situation and respond in what I determined to be the most appropriate way at any given time. This included remaining silent and allowing the participants the space to articulate how they were feeling or adopting a stance that conveyed that whilst I could not empathise with what they were feeling I could, through my own experiences, identify with them. In situations where the participants started to cry, I allowed time for the expression of the emotion but where I considered it appropriate I offered to terminate the interview. Finally, where I was concerned about the participants' well-being, I used the time after the interview to ensure, as best I could, that I was not leaving them with unresolved issues. On a practical level, I made the participants aware that it had been arranged that professional counselling was available through their healthcare provider should they feel they required it.

Nonetheless, although it could not be said to be an intentional outcome, there was little doubt that many of the participants found the conversations therapeutic. Several offered that they found it beneficial to tell their story and said they had not spoken with anybody else in the depth to which they did in the interviews.

this is really, the first time I've ever really spoken a lot about it...there's no one really here that I confide in a lot (Participant 4)

and when I read the bit about how bad I was in November...I haven't actually haven't cried since November...and I didn't cry much that day either. It was just to see it all in writing (Participant 6).

Related to this was my own boundary awareness about researcher and friendship. Some warn of the dangers of becoming overly involved (Kvale, 1996; Johnson and Clarke, 2003) and identify the potential risk to the researcher's emotional well-being (Dickson-Swift et al., 2006) and by association that of the participants. There is a risk that a dependency is created, which makes it difficult for the researcher to take their leave. Despite this, as my relationship with each participant developed, I perceived that I became emotionally involved with their situation. For example, I visited two of the participants when they were hospitalised as I felt I owed it to them to show concern for their situation and because they had taken the trouble to inform me. Whilst I acknowledge that the boundary between researcher and friendship may have been blurred at times, I concluded that it took place within the overarching parameters of the research relationship and on conclusion of the research, the participants and I were able to say goodbye.

An unanticipated ethical dilemma related to vulnerability was the participants' requests for information and advice about their condition and its treatment. Warren (2003) refers to these 'bombshells' as examples of foregrounding of the participants' agenda. Prior to conducting the interviews I was unaware of what each participant knew about their condition. It soon became apparent that many had a limited knowledge and part of their motivation for participating in the study was to seek information or ask my opinion about their treatment regimes. This resulted in disquiet on my part in the early stages of data collection because of the potential conflict between my role as a health practitioner and that of researcher, a finding also identified by Johnson and Clarke (2003). I was cognisant of their genuine need for information but I was also aware that I did not wish to impinge on their relationship with their healthcare providers. In order to resolve this matter, I accessed patient websites in the United Kingdom and printed off freely available material on chronic pancreatitis. I countered requests for information by making copies available after the interview. When asked my opinion on their treatment regime, I tried to answer honestly by stating that I was not an expert in the area and that they should make a note of their concerns to be addressed to their General Practitioner, Consultant or Specialist Nurse.

4.10.2 *Right to full disclosure*

The right to full disclosure is bound in the principle of the autonomy of the person, where the ability to make free and informed decisions is respected and based on the provision of full and accurate information (Holloway and Wheeler, 2002; Concone and Cerveny, 2008). In a research study, it is incumbent upon the researcher to ensure that the person's autonomy is protected and maintained, particularly where the person could be said to be vulnerable.

In this study, formal written disclosure began with the Information Sheet, which was distributed at the recruitment stage. It included information about the overall purpose of the proposed study and my role in it as well as the proposed procedures for data collection, their estimated commitment in terms of time, the measures for protecting their identity and their rights regarding the decision to participate or not. Although the format of the written information was, of necessity, in keeping with the guidelines of the research ethics committee, the information was written in plain language and in a style that avoided the use of confusing terminology and jargon and was directed to each potential participant, thus facilitating understanding. This written information was followed by an initial meeting for the purpose of clarifying any issues and answering questions, which I considered important for determining potential participants' understanding of what was involved. Although no formal method was adopted for determining their capacity or competency to make the decision to participate in the study, I considered it crucial to determine their comprehension of the commitment that was being asked of them. It also permitted the opportunity to meet in person and to some extent, began the process of rapport building. However, as stated earlier, five participants did not feel the need to have this initial meeting. Therefore, the time before the commencement of the formal interview was allocated to address issues of disclosure and their knowledge and understanding of the study.

Information disclosure to family members remained the responsibility of the primary participants because the decision to invite their participation in one

interview lay with them. However, I did produce a written information sheet for family members. In some instances, at the participants' behest, their spouses participated in the initial meeting even when they chose ultimately not to be involved. For family members who were not present at the initial meeting but with whom I conducted an interview, information disclosure took place prior to the commencing the interview.

Although this process defines the procedural requirements that must be undertaken in any research study, it was not a one-off event. Informal disclosure continued throughout the conduct of data collection. All participants were given my mobile phone number if they wished to contact me. I also started each subsequent interaction by exploring any information needs they had. Questions that arose were related to my interest in the topic, how I would manage the data and what I intended to do with the findings.

4.10.3 *Right to self-determination*

The right to self-determination is a fundamental premise whereby the person's decision to accept or refuse to participate in a study is entirely voluntary (Holloway and Wheeler, 2002; Guillemin and Heggen, 2008). The role of the researcher is to make the most honest effort to ensure that information provision and disclosure is sufficient to facilitate the person's free choice (Usher and Arthur, 1998; Länsimies-Antikainen et al., 2007) and to act with integrity by not engaging in any form of duress. Furthermore, it must be clear to participants that even if they do volunteer for the study, they retain the right to withdraw at any time without question or penalty (Orb et al., 2001).

In this study, the voluntary nature of the participation and the right to withdraw at any time was documented in written form in the Information Sheet and Consent Form and reiterated verbally at each meeting. However, whilst I believed I provided as much information as I could and I was not coercive or manipulative in any knowing way, I experienced some unease about the possibility that participants had some sense of obligation to participate out of gratitude to the consultant in charge of their care. I had informed them that the consultant had given me permission to approach them

and I speculated subsequently whether or not this was an undue influence. The only way in which I could counter it was to ensure that they knew their ultimate participation was unknown to the consultant and would have no impact on their care. Nonetheless, what this highlights is that in discharging their responsibility to inform participants of their freedom to choose, researchers need to bear in mind that there may be more covert influences at play.

Throughout the study, I had to determine the extent of the effort I would make to contact participants. For example, having returned transcripts to the participants I initiated contact. In some instances, where the contact number was a mobile phone, I was unsuccessful at the first attempt and some participants did not have a messaging service. As a result, I had to make a judgement about whether or not this was indicative of withdrawal from the study or if there were other events in the person's life that precluded their answering or receiving calls. For example, one man had to attend a family funeral in England and did not answer his phone. Ultimately, having explored the issue with my supervisor, I decided that where I could not leave a message, I would make one further effort to contact the participant after which I would withdraw. Over the course of the study, only one participant withdrew by failing to attend for our scheduled meeting.

4.10.4 *Right to privacy and anonymity*

In maintaining the principle of beneficence, a basic consideration is the preservation of privacy and anonymity in the conduct of the research (Orb et al., 2001). From a procedural perspective, this included the actions undertaken to conceal the identity of those who participated in the study and the hospitals and healthcare personnel involved with their care as well as the means of securely storing data and access to it.

However, in the practice of undertaking qualitative research complete anonymity cannot be assured by virtue of the fact that the participants are known to the researcher (Holloway and Wheeler, 2002; Parahoo, 2006). Therefore, my role was to ensure that outside the research relationship their identity remained unknown. To this end and as outlined above, I adopted

recruitment processes that guaranteed that the participants' ultimate involvement in the study was known only to them and their families, where they chose to tell them, and me. However, it transpired subsequently, that some had informed the hospital consultant that they were taking part. Whilst they were free to discuss their participation with whomever they chose, one participant's decision to do so led to an uncomfortable situation where his participation became known to a member of my family. Whilst I maintained my commitment to not discussing their involvement with anybody, this chance event had the effect of reinforcing the need for vigilance in removing potential identifying characteristics from the participants' stories.

To this end, the participants' names did not appear on recordings or transcript and each was identified by a numerical code. When writing their stories in Step 1 of the data analysis process the assignment of a number appeared to depersonalise the account. In this instance only, I attached an alphabetical code, which corresponded with their numerical code and was not related to their actual name. Given the geographical diversity of the participants and the likelihood that they and the hospitals they were attending could be identified, I removed references to named places and hospitals. Hospitals were assigned an alphabetical code for differentiation purposes in each participant's account but these bore no relationship to the same codes appearing in other stories. For example, Hospital A in Participant 1's story may not be the same hospital referred to as Hospital A in Participant 2's account. Names of healthcare personnel, family and friends were removed except in the written stories where references to close family members were given an alphabetical code. Rare or unusual characteristics or contexts peculiar to the individual were also removed as were biographical details that might contribute to identification of the individual.

In addition, all tapes and transcripts were stored in a locked cabinet in my home, where I was the only one with access. The informed consent records and the names and addresses of the participants were stored in a separate locked cabinet. Computer held transcripts and accounts were in a secure file that was password protected and stored in accordance with the Data Protection (Amendment) Act (Government of Ireland, 2003). These strategies

were outlined in the Information Sheet and discussed in detail prior to data collection.

In spite of these strategies, I was mindful that a further threat to privacy and anonymity lay in the writing of this report and the inclusion of excerpts of raw data therein. Given the nature of the service provided by the hospital, I was aware that it could be identified. Furthermore, chronic pancreatitis remains relatively rare and sampling from one hospital meant that the potential for identification of participants by members of the healthcare team was greater than in studies that use large numbers and wide sampling techniques. The issue that with some detective work, the location and participants in some qualitative research could be worked out was highlighted by Seymour and Ingleton (1999) in their studies. For me, this identified a further ethical dilemma. Do I report my findings faithfully and risk identifying the hospital and, by association, possibly the participants or do I omit or alter information so that identity is protected? Ultimately I believed that protecting the participants was my over-arching ethical goal and despite the obligation to provide rich description in qualitative research, contextual details and interview excerpts that could positively identify participants to those who know their medical history have been omitted.

An unanticipated issue concerned the confidentiality of disclosures made by one participant. At the beginning of one interview, he informed me that something he had said in the previous transcript had upset his partner. This caused me some alarm because I felt that had he not been in the study the situation would not have arisen. On reflection, I realised that the participants as autonomous adults could share the transcript with whoever they chose but were responsible also for the consequences of so doing. Any effort on my part to screen the content of the transcripts could be interpreted as paternalistic and/or dishonest. However, in a further interview, the same participant made further disclosures about which, he said, his partner did not know. When transcribing the interview I became concerned that if his partner read this material, there was potential for further discord. At this point, I felt it was my responsibility to remind the participant of what he had said. Therefore, I contacted him and gave him the opportunity to retract these statements

before I sent the transcript. My judgement was based on my awareness that in interviews participants may disclose aspects of their lives they later regret.

Whilst every effort was made to preserve the right to privacy and anonymity of the participants and their disclosures, I echo Baez's (2002) view that in qualitative research confidentiality is rarely watertight.

4.10.5 *Informed consent*

The four rights elucidated above essentially constitute the principles that underpin informed consent and therefore must be upheld in order for it to be said to have been obtained (Länsimies-Antikainen et al., 2007). They have been described as the pre-requisites for consent upon which potential participants undertake a decision-making process and the outcome of which is the decision to participate or not in the study (Länsimies-Antikainen et al., 2007).

In this study, initial consent was obtained and documented in written form and two copies of the form were signed by all participants (primary participants and family members) and me, with the exception of the family member with whom I conducted a telephone interview. In the latter case, consent was obtained via email. Although signed consent forms do not constitute informed consent, they meet the procedural requirements for documented evidence that consent has been given (Guillemin and Gillam, 2004). In keeping with these requirements, the consent form as a supplement to the Information Sheet included the title and purpose of the study, reiteration of the voluntary nature of the participants' contribution and their inalienable right to withdraw, the procedures for data collection and how they would contribute. That they had been given the opportunity to ask and have their questions answered and that there were no foreseeable risks or harm at the commencement of the study was also documented.

However, as evidenced by the complexity of the processes outlined above, informed consent is never clear cut in qualitative research as it can never be known fully what will happen or what will be uncovered in an interview. Therefore, initial written consent was supplemented with what has been

described as process consent (Rosenblatt, 1995; Walker, 2007). Process consent involves renegotiating consent throughout the participants' involvement with the study and encompasses an openness to co-constructing the ethical guidelines as the interviews progress. In this study, this meant that consent was not a one-off endeavour but involved continuous dialogue throughout. This included not only ensuring that participants' decisions to continue in the study were voluntary but also incorporated being ethically mindful of emerging issues and reflecting on strategies that would address these while preserving the ethical integrity of the study.

4.11 Integrity of the study

An essential feature of undertaking any study is determining its quality. Yet, the question of quality in qualitative research has been and continues to be a contentious issue (Emden and Sandelowski, 1999; Angen, 2000; de Witt and Ploeg, 2006; Rolfe, 2006). The debate originated in the implication that qualitative research studies by comparison with quantitative work are so rife with threats to validity that they are of no scientific value (Angen, 2000). When judged against the methodological rules and standards of experimental studies, interpretive work, in particular, is seen as lacking rigour and therefore legitimacy (Angen, 2000). Fundamental to this perceived lack of legitimacy is the relational position of qualitative to quantitative research, where the latter is still the dominant research modality in health sciences. This, according to Sandelowski (2008) results in a one-way comparison that simply re-asserts the 'deviance' of qualitative work.

The subsequent debates among proponents of qualitative research have focussed variously on whether or not to adopt quantitative criteria directly, to develop generic or method specific criteria or to abandon criteria for interpretivist approaches altogether (Angen, 2000; Morse et al., 2002; Watson and Girard, 2004; Mak and Elwyn, 2005; de Witt and Ploeg, 2006; Rolfe, 2006). Persuasive arguments have been presented in support of each stance, with the result that there are now numerous frameworks for assessing quality (Spencer et al., 2003), many of which are located in the work of Lincoln and Guba (1985) who established the foundation for criteria of rigour in qualitative work (Morse et al., 2002). Yet, rather than assisting researchers

in the field who are concerned with determining whether or not their study is good, this array of sometimes contradictory and conflicting frameworks can be confusing. In fact Morse et al (2002) argue that the issue of validity of qualitative work has become muddled to the point where it is almost unrecognisable.

Nonetheless, the ultimate aim of researchers is that they want to be sure they have done the right thing. Arminio and Hultgren (2002) argue that in qualitative research this is about determining 'goodness', which is an overarching principle embedded throughout the entire study and not confined to a post hoc standard evident only in the research report. Thus, the charge to researchers is to locate or develop criteria or standards that not only enable others to judge the quality of their work but also provide them with benchmarks against which they can evaluate the process as it is happening. Selecting appropriate criteria to represent goodness necessitates a return to the central argument of generic versus method specific criteria in qualitative research. The contention that the epistemic scope of qualitative methodologies is too broad to be represented by a single set of criteria (Sandelowski and Barroso, 2002) is, I believe, particularly relevant in hermeneutic studies. As Rolfe (2006) argues, aligning qualitative research with interpretivism and labelling it as a single paradigm that incorporates all non-quantitative research ignores the diverse ontological and epistemological positions therein. For example, Husserlian phenomenology, whilst using qualitative data collection methods, assumes an ontological and epistemological stance that is fundamentally different to that of philosophical hermeneutics. Therefore, even though there does not appear to be a final answer as to what constitutes goodness or how it can be judged (Emden and Sandelowski, 1998) the search for goodness criteria is about achieving an ontological and epistemological 'fit' with the nature of the study being undertaken.

This view is echoed in recent literature that argues for specific language and criteria that are consistent with the methodology of hermeneutic or interpretive phenomenology when determining rigour or validity (Moules, 2002; Lavery, 2003; Watson and Girard, 2004; de Witt and Ploeg, 2006). My

final choice of framework is an adaptation of that proposed by de Witt and Ploeg (2006) (Table 4.6) and is based on my belief that the criteria or expressions of rigour therein are consistent with undertaking a study using philosophical hermeneutics. However, I have adapted the characteristics slightly to reflect aspects of integrity highlighted by others that I believe are important. In addition, I have moved away from the empirical and analytical language of rigour (Arminio and Hultgren, 2002) and adopted the term integrity, whose meanings (honesty, wholeness and goodness) (Hawker, 2006) are congruent with Gadamerian philosophy (Watson and Girard, 2004).

Table 4.6: Criteria for Integrity in this study

Criteria/Expression of Rigour	Characteristics
Balanced Integration	Congruence between the philosophy, the researcher and the subject matter Inclusion of philosophical concepts within methods and findings Hearing the voice of the participants
Openness	Opening the study to scrutiny Orientation and attunement to the subject matter Understandable process Creative presentation (Angen, 2000) Believability (Moules, 2002)
Concreteness	Usefulness for practice
Resonance	The felt effect of the reading the study's findings on the reader
Actualisation	Potential/Promise The generative nature of the interpretations (Angen, 2000; Moules, 2002)

(de Witt and Ploeg, 2006)

4.11.1 *Balanced Integration*

In interpretive research it is essential to be cognisant of the philosophical underpinnings informing the particular approach being used and to adhere to these underpinnings consistently (Watson and Girard, 2004). As can be seen in Table 4.6, balanced integration is primarily concerned with achieving congruence between the philosophical underpinnings of the study, the topic of the research and the researcher. Moreover, it incorporates determining if the

philosophical underpinnings are intertwined throughout the study methods and findings (de Witt and Ploeg, 2006).

In this study, congruence began with an exploration and explication of my emergent understanding of hermeneutics and, having positioned Gadamer's philosophical hermeneutics within the evolution of modern hermeneutics, I presented a delineation of his key concepts. Van Manen (1990) states that this is important as the researcher should be able to articulate the theoretical and epistemological tenets of hermeneutics. Subsequently, in Chapter 3, I offered a clear explanation of why I considered there to be a fit between his philosophy, the subject matter of the research and me by determining how I would be positioned in the research, how I would engage with the subject matter and how I would establish meaning. I believe these strategies provided guidance for action and facilitated adherence to the philosophical underpinnings of the study throughout its implementation and in the presentation of the final meaning of living with chronic pancreatitis.

Furthermore, as I conducted the study, the intertwining of data collection and data analysis with Gadamer's philosophical tenets of hermeneutic circle, understanding and fusion of horizons were made evident throughout the processes of data collection, the subsequent choice of data analysis tool and the written explication of my decisions. In addition, I believe the strategy of simultaneously presenting and discussing the findings facilitated staying close to the voice of the participants, which were represented through excerpts from the raw data and were used to illustrate how their experiences were being conceptualised. Throughout, my emphasis was on achieving integration or harmony between the parts and the whole and arriving at the best possible interpretation. Furthermore, my final understanding reflects the tenets of Gadamerian hermeneutics in that it represents one interpretation but not a final one. I acknowledge the likelihood that others may interpret differently.

4.11.2 *Openness*

Openness is concerned with the strategies adopted to open the study up to scrutiny and to determine how the researcher remained orientated and attuned to the subject matter throughout the course of the study (de Witt and

Ploeg, 2006). Through these strategies, the outcome should be an understandable and creative yet believable account. In this study, two strategies I considered fundamental in achieving openness were rich and detailed description of the process of engaging with the subject matter and proceeding with the study, and reflexivity. Essentially, they are intertwined as both were essential in facilitating delineation of the decision making process throughout.

According to Angen (2000), interpretive research is a chain of interpretations that must be documented in order that others can make a judgement about the trustworthiness of the meanings achieved. Undertaking a study in the Gadamerian tradition lacks the benefit of a method and therefore it was imperative that the ethical and methodological decisions were explicated in sufficient detail to enable a judgement as to their coherence with the chosen philosophy. In structuring the report, the decisions taken at each stage, beginning from the construction of the research question to the final presentation of meaning and the implications of the study, have been explicitly outlined leaving a clear audit trail. The detail therein increases the transparency of the decision-making process and enables others to determine if these decisions were reasoned ones (Koch, 1996; Whitehead, 2004). This detailed description and explication, I believe has allowed the story to be told and will facilitate judgement by others of the moral soundness, honesty and integrity of the text and whether or not I have done justice to the subject matter. Although there are many interpretations and none are final, it is about whether the account has a sense of character that is recognised by the reader and is therefore, plausible (Moules, 2002). Ultimately, this decision belongs to the reader who determines if the story as it is told is understandable and believable.

Interwoven into these descriptions was reflexivity, which I believe is evidenced by the reflective nature of the whole of the account. This epistemological reflexivity encourages the researcher to reflect upon assumptions and their influence on the process of the research (Dowling, 2006). My understanding and the understandings derived from other sources, were explicated prior to undertaking the study in the documentation of my

prejudices and the literature review. Maintaining a reflective journal throughout facilitated openness to the participants and the subject matter and provided continual challenges to my emerging understanding. My changed and expanding horizons were detailed throughout the data collection and data analysis phases and in my conceptualisation of the findings and the final meaning.

As the instrument through which the meaning of living with chronic pancreatitis has been revealed, my endeavour throughout has been to present the process meticulously whilst simultaneously attempting to convey my personal involvement and passion for the subject matter. It has been suggested that in addition to elucidating these aspects, the researcher should possess creative and persuasive writing ability in order to produce a coherent and comprehensive account that impacts on the reader's understanding (Angen, 2000; Moules, 2002). While I cannot know if creativity is evident in the presentation of the report, I strived to present the participants' experiences and emergent conceptualisations in a lucid written form augmented by diagrammatic representation. In this way, I stayed close to the everydayness of their experiences and avoided the possibility of misrepresentation through overemphasis on the unusual, graphic or poignant (Thorne and Darbyshire, 2005).

4.11.3 *Concreteness*

Concreteness is an outcome criterion and may be distinguished when the reader recognises that the study findings are useful for practice (de Witt and Ploeg, 2006). At the time of completing a study, an individual researcher cannot determine if practitioners will deem the findings useful for their practice. However, I believe he or she can adopt strategies that will direct the reader thereby enhancing the possibility of making the connection.

According to Angen (2000) the focus of the research must be pragmatically informed from the outset if it is to have any practical lifeworld value. From the beginning, I grounded this study firmly within practice by describing how the question emerged from my clinical experiences and the care of patients with chronic pancreatitis. In doing this, I believe I established the immediate

relevancy for those who are similarly placed. Subsequently, in the literature review, I placed the subject matter within the social, cultural and health context of Ireland thus identifying the potential relevance for healthcare practice in this country. When presenting the findings, I offered examples of the participants' experiences that were likely to enable readers to make associations with their sphere of practice. In addition, drawing on the findings I identified parallels with the experiences of those with other chronic illnesses thus making the case for constructing chronic pancreatitis as a chronic illness within the wider social context.

4.11.4 *Resonance*

Resonance is also an outcome criterion that is concerned with the felt effect of the study's findings on the reader (de Witt and Ploeg, 2006). The written account should go beyond intelligibility and evoke a response in the reader that has been likened to an 'aha' experience, a 'smile of recognition' or a feeling of authenticity (van Manen, 1990; Angen, 2000; Cutcliffe and McKenna, 2002). As with openness and concreteness, it is incumbent on the researcher to attempt to create a written report that resonates with those that read it.

In qualitative research, obtaining recognition has been associated with the criterion of credibility and particularly the practice of returning the outcome of the findings (conceptualisations or less often theory) to the participants for the purpose of verification (Cutcliffe and McKenna, 2002; Tobin and Begley, 2004). However, the value of this 'member checking' has been questioned because of philosophical and epistemological concerns (Morse et al., 2002; Moules, 2002; Sandelowski and Barroso, 2002; de Witt and Ploeg, 2006). Cutcliffe and McKenna (2002) state that good qualitative research is much more than just description. The data have been analysed, interpreted and synthesised from and across individuals and the final conceptualisation is an aggregate of participants' perspectives (Morse et al., 2002). Therefore, participants may not recognise themselves or their experiences from this aggregation (Morse et al., 2002). Furthermore, in the time since the original interviews, participants may have changed their minds, new experiences may have intervened or the respondents may disagree with the interpretation

(Angen, 2000). Others argue that member checking is an attempt to establish a fixed truth that is in opposition to the principle in interpretive and hermeneutic research that meaning and understanding are temporal and co-created through dialogue and experience (Angen, 2000; de Witt and Ploeg, 2006).

Despite these arguments my original intention was to return a synopsis of the findings to the participants because I felt that, despite being an aggregate of their experiences, they should be able to recognise aspects of themselves. Moreover, I felt it would provide a form of validation that I had represented and interpreted their experiences in a meaningful way. However, the process of data analysis and the final interpretation was not complete until a year after the data collection phase ended. As a result, the matter of returning the findings became an ethical issue. I experienced disquiet about contacting the participants because I had no idea about what had happened to them in the intervening time and I was concerned about causing distress to participants or their families should their health status have altered significantly.

After considerable reflection I concluded that my desire to return the findings was related to an innate lack of confidence about what was, essentially, 'my' interpretation and my desire to be seen to do the 'right thing'. However, mapped against what I believed now could be a potentially harmful act I chose not to contact the participants or return the findings. Furthermore, having returned the transcripts following each interview and engaged in dialogue, explanation and discussion about their content with the individual concerned, I believe the meaning of living with chronic pancreatitis as conceptualised in this study has remained faithful to the participants' experiences.

4.11.5 *Actualisation*

Actualisation is the final outcome criterion and refers to the 'potential' or generative nature of the research study (Angen, 2000; Moules, 2002; de Witt and Ploeg, 2006). Interpretive research can move readers beyond their present understanding of the subject matter and when combined with their experiences and perspectives can lead to new interpretations (Angen, 2000).

It has been referred to as the future realisation of the resonance of the study findings (de Witt and Ploeg, 2006). The generative possibilities of this study begin with the presentation and discussion of findings and the interpretation presented therein. From these, the implications for practice, education and future research are extrapolated in the final chapter of this report and constitute my reflection on the possibilities or potential of this study. However, in acknowledging that mine is but one interpretation and by inference so too are the implications, my request to readers is that they give consideration to how this interpretation can be affirmed or moved beyond its current focus and vision.

4.12 Conclusion

This chapter was an elucidation of how I engaged with the operationalisation of the hermeneutic inquiry into the meaning of living with chronic pancreatitis. Having outlined the research question, aims and objectives, I presented an exposition of my prejudices regarding the subject matter. The practical conduct of the study was presented and included discussion of issues related to sampling, recruitment and access. The processes of data collection and data analysis were described in detail in order to illuminate my decision-making and document how I came to the final interpretation of the meaning of living with chronic pancreatitis. Pertinent ethical issues were explored and designated as ethical integrity. The chapter concluded with a critical analysis of the rationale for and selection of the criteria for judging and achieving the overall integrity of the study. Through reflexivity, I attempted to represent the challenges and possible limitations of this inquiry and how I endeavoured to meet them.

The final stages of the process of analysis depicted as explication of the expanded meaning and representing shared understandings are presented in the following two chapters. Supported by reference to pertinent and indicative literature, the first of these chapters examines the three unifying categories of enduring physiological disruption, enduring social disruption and enduring psychological disruption that symbolise enduring (permanent or perpetual) disruption and interpreted to represent 'suffering'. Subsequently, in the second chapter, the meaning of endure, 'to cope with' and/or 'to tolerate'

discusses how the participants and their families 'come to know', and 'adjust/manage' through the development of self-management strategies within an overall transition from 'well' person to a person who lives with chronic pancreatitis. Together these form the whole of the meaning of living with chronic pancreatitis.

CHAPTER 5 – PRESENTATION AND DISCUSSION OF FINDINGS

ENDURING DISRUPTION – ‘PERPETUAL AND PERMANENT DISRUPTION’

5.1 Introduction

The presentation and discussion of findings is divided into two chapters to facilitate elucidation of the two-fold nature of the concept of ‘enduring’. The first chapter focuses on the nature of ‘enduring’, as an adjective, meaning perpetual and permanent disruption and explores the three unifying categories of ‘enduring physiological disruption’, ‘enduring social disruption’ and ‘enduring psychological disruption’. The second chapter concentrates on the second meaning of ‘endure’, in terms of ‘to cope with’ and/or ‘to tolerate’ and explicates how the participants and their families ‘come to know’, and ‘adjust/manage’. Themes and codes within and across each category are used as the basis for exploration and are illuminated with excerpts from the raw data. Pertinent and indicative empirical literature identified through and related to the findings is incorporated to facilitate further interpretation and advance understanding of the participants’ and their families’ experiences of living with chronic pancreatitis.

This approach is chosen in order to elucidate the detail of enduring disruption but with the rider that the divisions between the categories are in a sense false ones given the iterative relationship between them.

5.2 Literature Search

Prior to commencing the discussion a computer based literature search was undertaken using Pubmed as the primary database but expanding where necessary into Proquest, Science Direct, Ovid, Blackwell Synergy and Sage Publications. Following retrieval of literature, manual searches were undertaken for completeness and further texts were sourced. For the purpose of comprehensiveness, no date limits were applied to these searches although the focus was primarily on publications during the last ten years.

Initial search terms were identified from the themes that emerged from the data analysis¹². Ultimately, these were grouped under the three unifying categories. Therefore, the search terms corresponded with the subject matter for that category. The terms were entered independently and in conjunction with 'chronic pancreatitis'. As a result of this strategy no additional or new literature related to chronic pancreatitis was identified, other than that which had been previously sourced. However, a plethora of literature and studies related to a range of chronic illnesses (cancer, chronic pain, Crohn's disease, cystic fibrosis, diabetes, fibromyalgia, Hepatitis C, HIV/AIDS, lung disease, multiple sclerosis, renal failure, rheumatoid arthritis, scleroderma) was identified.

The literature is mainly comprised of studies that are qualitative and quantitative in design and located primarily within the disciplines of nursing, medicine, psychology and sociology. Supporting literature includes seminal texts such as that of Charmaz (1983), Lazarus and Folkman (1984), Anderson and Bury (1988), Kleinman (1988) and Izard (1991) and related social or government publications or reports.

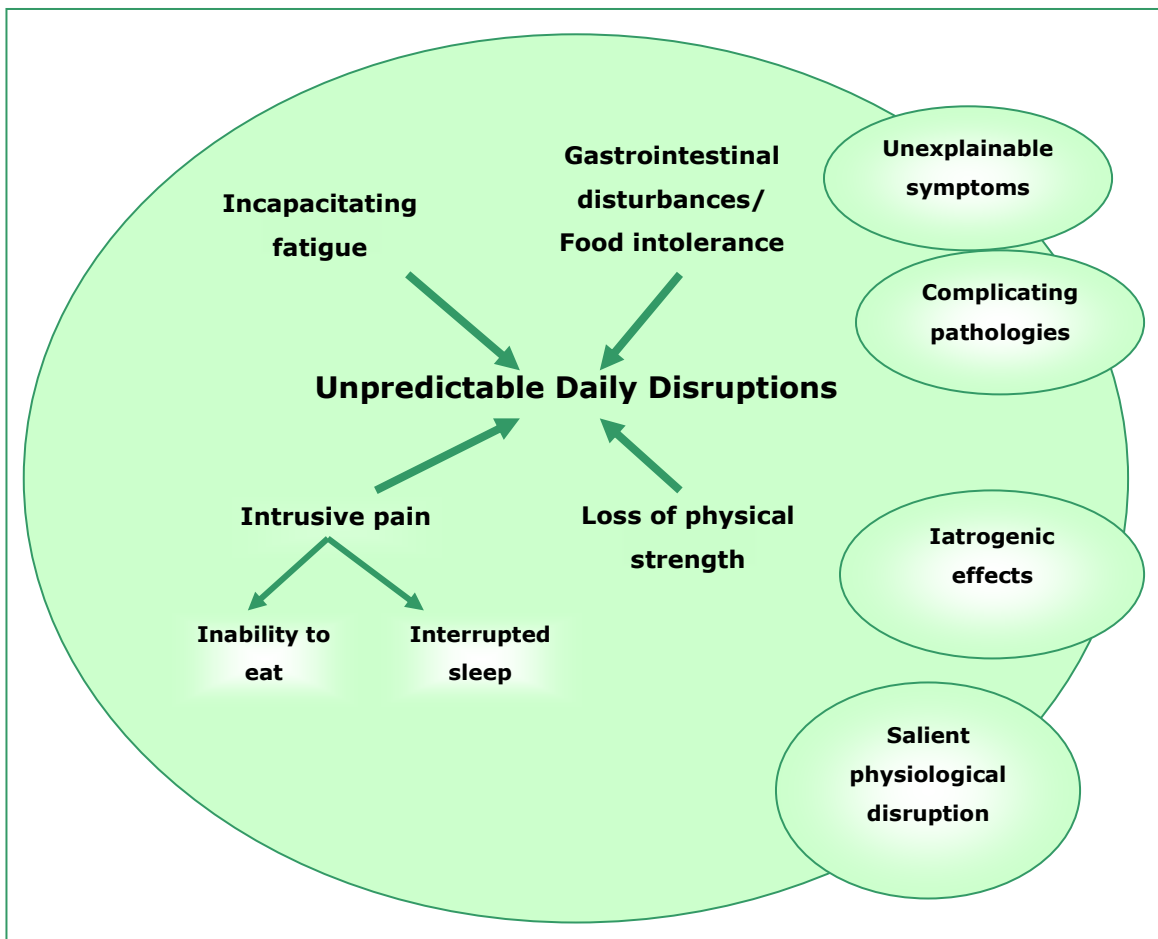
An important point is that the literature searching and retrieval was not a single event and continued throughout the writing of the discussion of findings.

¹² These themes encompassed each of the Tree Nodes and included: altered economic circumstances; altered self in illness; altered social relationships; coming to know; emotional coping; interacting with healthcare professionals; negotiating the welfare maze; 'new' normal; personal relationships; redefining 'self'; seeking health care help; self-management; social resources; unpredictable daily disruptions.

5.3 Enduring physiological disruption

For the participants in this study, perpetual and permanent physiological disruption manifests itself in the form of unpredictable daily disruptions that are interspersed with episodes of escalating or salient physiological disruption (Figure 5.1). The enduring nature of the disruptions is evidenced by the reality that no participant experiences a day in which they are without some indication that the condition exists. However, in keeping with the uncertain illness trajectory of chronic pancreatitis, these disruptions vary in frequency and intensity from person to person and in the interplay between daily disruption and escalating or salient disruption, both of which are wholly unpredictable.

Figure 5.1: Enduring physiological disruption



5.3.1 The Beginning – Initial salient disruption

For all participants in this study, the process of being diagnosed with chronic pancreatitis began with salient disruption.

I woke with quite a severe pain in my left hand side. I didn't feel nauseous, but when I ate a small amount of breakfast I had to leave the table and that came back up the way it went down. The pain continued until lunch time, the same thing happened and at tea time, the same thing happened (Participant 11 – Interview 1)

Rarely, however, was the initial salient disruption attributed to chronic pancreatitis. A possible reason for this corresponds to some extent to the documented difficulties with diagnosing early chronic pancreatitis (Tinto et al., 2002).

the word pancreatitis was mentioned to me by a GP in Wales...but (Consultant's name) in (hospital name) checked for acute pancreatitis but there was no amylase increase so, the whole pancreatitis issue was floored (Participant 7 – Interview 1)

Furthermore, diagnosing rare forms of the condition is complex as was evidenced in the case of one participant whose initial diagnosis was terminal pancreatic cancer. Autoimmune chronic pancreatitis is a benign condition rarely diagnosed pre-operatively and usually detected intra-operatively in patients undergoing pancreaticoduodenectomy for a presumed pancreatic adenocarcinoma (Gumbs et al., 2005). For the participant in this study, if the initial palliative regime had been followed, she is likely to have died.

when they autopsied people who died of cancer they realise that there wasn't cancer there in the first place. And basically that was the road I was going down (Participant 9 – Interview 1)

In other instances, pancreatitis, acute or chronic was not considered during medical consultations and a diagnosis of 'ulcers' or 'gastritis' was more commonly made.

he brought me straight up to the doctor and he thought it was ulcers (Participant 8 – Interview 1)

and I left it go for possibly maybe 12 months before I went to my doctor...he did treat me for a peptic ulcer, which I have no doubt that it never existed (Participant 13 – Interview 1)

Others attributed gastrointestinal disturbances to existing co-morbidities or temporary conditions or circumstances such as 'food-poisoning' or 'tiredness'. These judgements were reinforced when symptoms settled but on reflection and following diagnosis, were deemed possible indicators of the developing condition.

I put it (pains in back) down to tiredness...from all the driving. Because that's the time I was driving probably 1000 miles a week (Participant 10 – Interview 1)

In some cases, pain and vomiting after a period of heavy drinking, was attributed to the after-effects of alcohol and medical assistance was not sought.

thought I had a hangover – I was used to that...the body going into shagging withdrawal, I'd binge – at that stage I was starting to binge sort of week/two weeks long (Participant 3 – Interview 1)

However, where medical assistance was obtained, the assumption that alcohol was a factor was supported and advice was given regarding abstention, but a possible link to pancreatitis was not made. In these instances, the presence of a possible alternative explanation seemed to obviate the need for further investigation.

I would have episodes of drinking, say maybe three day or four days heavy, heavy drink...somebody who has just a hangover and they get sick for twelve hours and that's it. This could go on for

three days and that was why I was wondering if that could be part of the pancreatitis mechanism. I would be violently, violently sick and have been hospitalised on several occasions for rehydration because of it (Participant 11 – Interview 1)

Consequently, eleven of the fourteen participants experienced delay in receiving a diagnosis of chronic pancreatitis. In the intervening time, they experienced continuous or episodic salient disruption and presented on more than one occasion to their General Practitioner or Accident and Emergency departments.

I probably had the condition maybe a year before the diagnosis – it was misdiagnosed as gastritis – so I would probably say I had about three acute attacks before it was fully diagnosed (Participant 1 – Interview 1)

During this pre-diagnosis phase, participants experienced what they consider to have been unnecessary prolonged pain and disruption. For many, it was during this time that the most profound alteration to their physical appearance occurred. Uncertainty as to the threat to their well-being and a sense of powerlessness intensified feelings of anxiety. As a result, they or their families began to question the diagnoses they had been given and in some cases speculate on alternatives that are more sinister.

he was so sick. He was grey, your pallor was grey, an awful lot of your friends thought you were on your last legs (Family member – Wife)

Because of these disruptions, all participants, except one, were hospitalised on several occasions. For seven of the participants, the severity of the attacks necessitated intensive care treatment, mechanical ventilation and dialysis due to organ failure. For most, it was during these hospitalisations that the diagnosis of chronic pancreatitis was made.

5.3.2 Unpredictable daily disruptions

Primary daily disruptions include intrusive pain, gastrointestinal disturbances and food intolerance, incapacitating fatigue and loss of physical strength. These appear to exist independently of each other, whereas significant but secondary disruptions are interrupted sleep and inability to eat arising directly from the presence of pain. Superimposed on these primary and secondary disruptions are complicating or co-existing pathologies, unexplainable symptoms and iatrogenic effects of a variety of medications but principally analgesia, which deals with the pain but often leaves undesirable effects behind.

5.3.2.1 Intrusive Pain

Despite variations in the patterns and intensity of disruptions, pain is universal among the participants and the most noxious symptom. The general perception of the pain is that it is quite distinct and unlike any pain experienced before. As one participant said:

it's not something I'd confuse with wind (Participant 3 – Interview 1)

Additionally, its intensity appears to defy description. Whilst participants are clear that they recognise it as being the pain of chronic pancreatitis, they often spoke of how difficult it was to describe, a finding also reported in Öhman et al's (2003) study of several chronic illnesses. Various analogies were used to try to articulate what it was like.

it's actually quite difficult to describe it...nothing compares really to CP pain (Participant 1 – Interview 1)

oh the pain – nothing as bad...a toothache is nothing as bad...that's not pain compared to the pancreatic pain (Participant 2 – Interview 2)

I had shingles one time down my face, I thought that was the worst pain you can get – nah, the pancreas is the worst (Participant 8 – Interview 3)

The nature of pain was described variously as:

it's a pain usually starts there (indicating on abdomen) and then spreads and it shoots out through the back and if you move that way it'll shoot across that way and if you move that way it'll move across that way and what you literally do, you get into position and you just freeze there – you might get a small bit of ease from it (Participant 8 – Interview 1)

These descriptions are associated largely with the remembered pain of persistent acute episodes. In contrast, everyday pain is described as 'abdominal tenderness', 'discomfort' or 'low to mid-level pain' where the nature of the pain is similar but differs in its intensity, a 'constant nagging draggy down pain' (Participant 10 – Interview 3). This everyday pain acts as a constant reminder of the existence of the condition but is largely tolerable.

the low level pain I can handle it reasonably well...I've got quite used to (it)...I know when it's coming on and I can work around it (Participant 1 – Interview 1)

Although this suggests a simple division between acute and everyday pain, the reality for the participants in this study is that the intensity of the pain fluctuates on a continuum from everyday tolerable pain to acute and sometimes unendurable pain. While at times these fluctuations can be attributed to an individual's behaviour, for the most part they are unpredictable and unexplainable. The unpredictability is that the pain can escalate at any time on any given day for no evident reason. Equally, it may resolve and settle but the pattern or the outcome cannot be foreseen.

I feel some sort of pain every day. At any given time I could be in pain for five minutes and the rest of the day could be grand. There

could be another day, no relief whatsoever – it's pain from the minute you get up till you fall asleep or you don't fall asleep (Participant 5 – Interview 2)

These findings are consistent with medical claims about the unpredictable and changeable nature of pain and pain patterns in chronic pancreatitis (Fitzsimmons et al., 2005; Gupta and Toskes, 2005; Sareen et al., 2007) and are linked with a continued lack of certainty as to its pathogenesis and the progression of the condition. What is evident for the participants in this study is that pain, regardless of its intensity, is a constant intrusion in their everyday living. Although pain is not a feature of all chronic illnesses, similar findings are reported in nursing and sociologically based studies where pain, when it exists, is considered as the major symptom or significant stressor that impacts negatively on participants' lives (Bury, 1988; Kleinman, 1988; Moore Schaefer, 1997; Carson and Mitchell, 1998; Melanson and Downe-Wamboldt, 2003; Öhman et al., 2003).

Interrupted sleep

While enduring and unpredictable pain is distressing, its impact is compounded by its effect on the person's ability to sleep; 'if I get half an hour I'm doing well' (Participant 3 – Interview 2). The greater the intensity of pain the more likely it appears that sleep is interrupted.

I came down here because of the f***ing pain – sitting up like that – a good three or four hours taking Solpadeine – every f***ing thing out of the press (Participant 12 – Interview 2)

Pain is a factor that has long been associated with disturbed sleep (Alexander et al., 2006). It is generally accepted that sleep quality has a restorative purpose (Edéll-Gustafsson et al., 2003) particularly in the maintenance and/or restoration of cerebral and physical functioning (Alexander et al., 2006). Disturbances in activity-rest and sleep-wake patterns (circadian rhythms and circadian processes) because of chronic or partial sleep deprivation are associated with decreased human functioning (Redeker et al., 2004). For participants in this study, the exhaustion from interrupted or decreased sleep

is seen as debilitating both physically and mentally. Thus, participants make efforts to rectify sleep loss when the pain has dulled or is tolerable.

the main kind of problems with that pain are.... a) it's very difficult to get to sleep and b) it's very difficult to stay asleep so that I'll only get to sleep when I'm sort of completely exhausted ...the pain actually wakes you up – that's very debilitating because you're exhausted as well as being in pain...and it makes your ability to fight the pain go downhill (Participant 1 – Interview 1)

Inability to eat

A further physiological consequence of pain is a perceived inability to eat. This is distinct from gastrointestinal disturbances as in some situations choosing not to consume food is a direct consequence of the presence of pain. Food avoidance when participants are experiencing low-level everyday pain seems to be an instinctive reaction.

if it's a constant gnawing pain...we'll say a 2 to 4 – I call it a sensation...it's telling me 'don't eat anything (Participant 13 – Interview 3)

However, when the pain escalates participants feel they are unable to tolerate food because it appears to induce or exacerbate the pain further.

I've often had pains for six/eight days at a time and wouldn't be eating, just maybe having a cup of Bovril with an odd slice of bread dipped into it – I wouldn't actually be eating anything apart from that 'cause I wouldn't be able to (Participant 14 – Interview 3)

Yet, the awareness of the need to eat in terms of meeting nutritional requirements is an intervening factor even in the presence of pain. As one family member described it:

he just tries to get enough food down to stay alive (Family member)

In these instances, participants appear to make a judgement based on a perceived risk/reward strategy. If it is deemed that the pain will remain within tolerable limits, where possible they will continue to eat for the purposes of attempting to maintain their nutritional intake.

I eat because it's been eight hours since I last ate ...and I know I have to try and get some nutrition in but I don't actually feel like eating so you're having to force the food in, it's not sitting well... you don't have your kind of normal healthy appetite (Participant 1 – Interview 3)

For these participants, the stimulus to eat seems to be associated with actual or perceived weight loss whereas for those whose weight has remained stable following the initial onset of the condition, it is less of a concern. This appears to be because body weight is associated with the concept of wellness. Regaining weight is seen as positive and indicates some level of recovery.

This view is consistent with the literature where weight loss is considered a significant factor in the development of malnutrition in chronic pancreatitis (Bornman and Beckingham, 2001) and is one of the clinical indicators of advanced structural damage to the pancreas (Lankisch, 2001; Layer and Keller, 2002). Nonetheless, maintenance of body weight does not exclude the existence of biochemical malnutrition and must be considered with other factors such as malabsorption because of food intolerance and gastrointestinal disturbances (Sareen et al., 2007).

5.3.2.2 Gastrointestinal disturbances and food intolerance

Food intolerance and gastrointestinal disturbances are also a universal feature of the daily disruptions of the participants in this study. Food intolerance incorporates loss or lack of appetite (anorexia), difficulty with digestion (maldigestion) and in some cases a psychological aversion to some foodstuffs. Gastrointestinal disturbances include a range of symptoms such as abdominal bloating, nausea, vomiting and altered bowel function (constipation, diarrhoea, steatorrhoea).

Although loss or lack of appetite is sometimes attributed to the presence of pain, for many of the participants, it can only be ascribed to a vague sense that not all is well. Thus, they do not feel like eating.

I think that day to day now I feel like... if you'd had a bad curry or if you've had a slightly dodgy meal and you have slight indigestion or something (Participant 4 – Interview 2)

More specific symptoms of abdominal bloating and nausea can be present prior to or as a result of eating per se. In either case, participants are unwilling to aggravate these symptoms and when they are unpleasant, they abstain from food. At other times, the mere thought of some foods induces nausea.

very bad swelling of abdomen – bloated out after dinner. Do not want to eat much at all...don't like to eat...feeling nauseated, sickish feeling (Participant 13 – Diary entry)

For all participants, certain foodstuffs are avoided either because they are high in fat or are difficult to digest. Maldigestion, the ability to digest complex foods and malabsorption of proteins or fat are associated with exocrine insufficiency of the pancreas but are not deemed clinically significant until over 90% of the function of the gland is lost (Mergener and Baillie, 1997). Given that the participants in this study self-reported these symptoms, the clinical significance in terms of exocrine insufficiency cannot be determined. The long-term pathophysiological implications were not a feature of their discourse and so it is assumed that they are an unknown. For them, the significance is that they experience pain, bloating, nausea, vomiting, diarrhoea and steatorrhoea at varying intervals.

I've become so sensitive to what I eat...if I eat something maybe that I shouldn't or just eat crap...it really has an effect (Participant 4 – Interview 2)

...constipationevery holiday I start off the week normal and by the end of the holiday I just feel like I'm, I have four stone of s***e inside of me (Participant 7 – Interview 3)

5.3.2.3 Incapacitating fatigue

Fatigue is a common symptom experienced by those with a range of chronic illnesses (Rose et al., 1998; Trendall, 2000; Glacken et al., 2003; Öhman et al., 2003; Thorne et al., 2003; Kralik et al., 2005) but is differentiated from that which is described as acute or as seen in a healthy individual (Jorgensen, 2006). The fatigue of a normal healthy individual is induced by activity or exertion and is relieved by sleep, rest and/or nutrition (Trendall, 2000). Fatigue is also a feature of acute illnesses but for the most part resolves with recovery. The critical attributes of chronic fatigue identified by Trendall (2000) in her concept analysis and the reports from research studies into fatigue in various chronic illnesses (Moore Schaefer, 1997; Rose et al., 1998; Asbring, 2001; Glacken et al., 2003; Thorne et al., 2003; Kralik et al., 2005; Jorgensen, 2006) correspond with the features of incapacitating fatigue articulated by the participants in this study (see Figure 5.2).

The findings of this study are similar to recent chronic pancreatitis studies where fatigue has been recognised as a determining factor in the assessment of quality of life (Wehler et al., 2004; Fitzsimmons et al., 2005). However, given the nature of the descriptions articulated by the participants it is argued here that a more accurate definition would be one of 'chronic fatigue'. Yet, within this classification, further specificity of its presentation in chronic pancreatitis is needed since the manner in which it manifests itself or is experienced is not standard across all chronic illnesses. Accurate assessment of its impact on those living with chronic pancreatitis would facilitate the possible development of effective interventions and strategies for its management.

Figure 5.2: Critical attributes of chronic fatigue versus incapacitating fatigue in chronic pancreatitis

Critical attributes of chronic fatigue	Incapacitating fatigue in chronic pancreatitis (excerpts)
<p>A subjective, internal and unpleasant feeling (Trendall, 2000; Kralik et al., 2005; Jorgensen, 2006)</p>	<p>'I don't know what it is but I've pains all over me...I just feel rotten. Now whether it's that or whether it's something else I just feel rotten. I'm exhausted' (Participant 6 – Interview 2)</p> <p>'I don't have the energy to repeat myself so much, that I have to get this known first time it's said, so you have to hear it the first time I say it because there is no more energy to follow it again' (Participant 7 – Interview 1)</p>
<p>Affects physical, mental and emotional dimensions (Rose et al., 1998; Trendall, 2000; Glacken et al., 2003)</p>	<p>'Your ability to kind of fight the pain go downhill because you're run down and you're exhausted the whole time' (Participant 1 – Interview 1)</p> <p>'you don't do anything because of it' (Participant 5 – Interview 2)</p> <p>'But everything now is such an effort to me...if I have to do anything I'm nearly crying doing it' (Participant 6 – Interview 2)</p> <p>'Really tired no energy' – wretched tiredness' (Participant 10 – Interview 1)</p>
<p>Does not resolve with rest and nutrients (Trendall, 2000; Glacken et al., 2003; Jorgensen, 2006)</p>	<p>'when I wake up some mornings I don't feel like...you think you haven't slept at all (Participant 10 – Interview 3)</p>
<p>An overwhelming desire to sleep and rest (Rose et al., 1998; Trendall, 2000; Kralik et al., 2005; Olsson et al., 2005; Jorgensen, 2006)</p>	<p>'I could go to bed now and not wake up until the morning' (Participant 6 – Interview 2)</p> <p>'I know I promise to bring them (children) out but you just feel worn out and she says, 'you're not going to go to sleep already' (Participant 12 – Interview 1)</p>
<p>Decreased motivation and interest in surroundings (Trendall, 2000; Jorgensen, 2006)</p>	<p>'I just can't muster up any enthusiasm for it' (Participant 10 – Interview 2)</p> <p>'When I first moved into the house, I'd be going mad to fix and doing something now I just don't have the energy, I'm not in the mood – 'oh I'll do it next week or tomorrow'' (Participant 12 – Interview 1)</p>
<p>Decreased capacity for physical and mental work (Rose et al., 1998; Trendall, 2000; Kralik et al., 2005; Jorgensen, 2006)</p>	<p>'it's so hard to describe...I just have not got an ounce of energy, like I nearly have to crawl up the stairs...even if I do the polishing it really wears me out' (Participant 6 – Interview 2)</p> <p>'I haven't got the physical stamina that I had' (Participant 7 – Interview 1)</p>

Critical attributes of chronic fatigue	Incapacitating fatigue in chronic pancreatitis (excerpts)
	'Wanted to work in garden but couldn't work up energy' (Participant 13 – Diary entry)

5.3.2.4 Loss of physical strength

Some participants referred directly to loss of physical strength as a feature of their living with chronic pancreatitis as differentiated from the identified lack of stamina or energy associated with fatigue. Loss of physical strength was attributed to a perceived loss of muscle bulk following significant weight loss. The references to loss of physical strength were confined to the discourse of the men in the study whereas the women tended to use language associated with the concept of fatigue. Whether this was a gender related issue in terms of perception of physical self is speculative. In those participants who experienced what they determined as significant weight loss there is a suggestion of an analogous relationship with the loss in physical strength.

all my muscle is gone – I had muscles and now I have nothing – nothing, there is only bone – all shrunk (Participant 2 – Interview 1)

he feels he is not able to work as much as he used to. He is much weaker and cannot do as much as previously (Participant 13 – Interview 4 researcher's notes)

The presence of a degree of cachexia in those with chronic pancreatitis has not been specifically addressed although Mergener and Baillie (1997) suggest that the 'typical' patient is thin, sometimes emaciated and may have the appearance of having a malignant disease.

In chronic pancreatitis, weight loss is strongly associated with maldigestion of fat (Meier and Beglinger, 2006) and Gupta and Toskes (2005) assert that restoring a patient's fat absorption to an acceptable level permits weight gain through a reduction in diarrhoea and steatorrhoea. Yet, the participants in this study believe that the loss of weight and physical strength is a permanent consequence of living with chronic pancreatitis.

The significance of a loss of physical strength was determined as a loss of ability to function effectively in their physical role (Wehler et al., 2004; Fitzsimmons et al., 2005). When considered in conjunction with the effects of chronic fatigue, loss of physical strength is seen as debilitating.

5.3.2.5 Iatrogenic effects

Superimposed on primary and secondary unpredictable daily disruptions are iatrogenic effects, associated principally with the consequences of prescribed medication although one participant reported the development of a postoperative hernia. While iatrogenesis can refer to both good and bad effects, the participants' perceptions that prescribed medication aggravates their daily disruptions, means that the emphasis is mainly on the negative aspects.

when I was in hospital, they brought the patch forward another day – instead of losing a day's sleep every three days, it's every two now...I said that to him out there and he said, basically like, tough luck, tough s*** like. I said 'I won't be able to sleep now every two days' and he said, 'it's either that or put up with the pain' (Participant 5 – Interview 2)

For the most part, the participants perceived they had little option but to live with the side-effects of analgesia since being without pain-killing medication could not be contemplated. However, patterns of usage varied between them depending on the level of pain they were willing to tolerate versus the undesirable effects of the analgesia.

even Solpadeine or anything like that – all these Anadin Extra and all that – I don't take them...I don't know what way tablets might affect the liver but obviously they don't agree with it or do some kind of damage to it (Participant 12 – Interview 3)

Opioids are recommended for moderate to severe pain of a visceral nature (Joint Formulary Committee, 2007) and are the mainstay of analgesic therapy in this group. Three participants did not have prescribed analgesia at the time

of the study. Of these, only one described herself as pain free whilst another accessed analgesia through her general practitioner as needed. Prescribed analgesia was contra-indicated in the third participant because of concern about further liver damage.

The range of opioids and method of administration vary but initial medication is often in the form of Tramadol orally. Where this was deemed ineffective participants were prescribed continuous slow release tablets orally or transdermal patches. Nerve blocks were used unsuccessfully with two patients. Supplementary medication such as non-steroidal anti-inflammatory drugs is used sometimes. Anxiolytics and hypnotics are also used to facilitate relaxation and sleep, often in the face of uncontrolled pain. Despite concerted efforts, eight of the eleven participants receiving medication felt their pain was not adequately controlled. Of these, three had been referred to a specialist pain team but at the time of the study, the participants could not report any meaningful improvement in their pain status.

The key side-effect of opioid medication reported by the participants is drowsiness, although gastro-intestinal pain/discomfort, constipation, mood changes and risk of addiction were also mentioned. While not listed as known side-effects of tramadol, one participant referred to appetite suppression and inducement to smoke cigarettes. Other known side-effects such as nausea and vomiting and sweating were not attributed to the medication but this may have been because they were indistinguishable from their occurrence in chronic pancreatitis. The consensus among the participants was that they 'did not like' taking analgesia because of an underlying belief that all medication was ultimately harmful - 'I'd rot the stomach out of myself' (Participant 8 - Interview 1).

Others appeared to have a clearer understanding of the issues related to dependence or addiction. The participants who were medicated with transdermal opioid patches were aware, from experience, of the problems of withdrawal from the medication.

I mean you're already in a pretty bad straits if you've got CP...I'll take my chances with opiate addiction rather than tearing your hair out with pain...I mentioned about stopping the Buprenorphine patches, ...a nasty withdrawal kicked in for a couple of (days), really, really uncomfortable and your skin, couldn't sleep (Participant 1 – Interview 3)

In respect of other medication, only one participant reported perianal irritation, which is associated with excessive doses of pancreatin (Joint Formulary Committee, 2007). Even though this effect may appear innocuous, the perianal irritation interfered significantly with this participant's ability to sleep. Additionally, he felt unable to increase his dosage of Creon as this further exacerbated the perianal irritation – 'its embarrassing, I get a terrible itch in my bottom from doubling up on the Creon' (Participant 10 – Interview 1). As a result, he lost more weight due to malabsorption and experienced further abdominal discomfort. Thus, his living became more severely disrupted.

Another participant, whose chronic pancreatitis was attributed to hyperlipidaemia, had a reaction to several statins, which were ultimately discontinued despite the cardiovascular risk from raised cholesterol.

I was on cholesterol tablets and I went to casualty several times, thought the pancreas was off again – the cholesterol tablets were tearing the lining of my stomach...eventually last year they just stopped giving them to me – they were actually causing more damage (Participant 14 – Interview 1)

Participants, therefore, are in the invidious position of trying to balance the need for pharmacologically based treatments of symptoms of the condition against their potentially distressing side-effects. Essentially, they are choosing between side-effects that tend to exacerbate pre-existing symptoms such as fatigue or enduring pain. Regardless, both options aggravate daily disruption. A complicating factor is the reality that their knowledge of their pharmaceutical preparations is limited and their learning largely experiential.

The situation is compounded by the presence of what are described as unexplainable symptoms and complicating or co-existing pathologies. The process of deducing whether their manifestations can be attributed to chronic pancreatitis, pharmacological treatments or complicating or co-existing pathologies is endless.

5.3.2.6 Unexplainable symptoms

Unexplainable symptoms are those occurrences for which participants could not account within the realms of their current knowledge.

I was driving today in the van and the sweat was pouring down me...for no reason (Participant 10 – Interview 1)

went to my GP and said I don't know whether it's the weather because I was perspiring profusely and I just had absolutely no energy. I was eating nothing (Participant 11 – Interview 1)

The important factor here is not that the symptoms are not explainable per se but are processed within the limits of the participants' understanding and therefore, not explainable by them. At a physiological level, these events are unpleasant and accentuate daily disruptions. More significantly perhaps is that they engender a fear that they are indications of physiological complications.

5.3.2.7 Complicating-co-existing pathologies

Complicating or co-existing pathologies overlay daily disruptions in those living with chronic pancreatitis. Although there are a number of major morphological complications of chronic pancreatitis (Gupta and Toskes, 2005), from the perspective of the experience of the participants in this study, diabetes mellitus is the most significant in their daily lives.

In this study, five of the participants had been diagnosed with diabetes mellitus, which is a chronic illness independent of chronic pancreatitis and

carries with it life-threatening complications associated with severe hypoglycaemia (Angelopoulos et al., 2005) and chronic long-term complications due to macrovascular and microvascular degeneration (National Institute of Clinical Excellence, 2002; Nair, 2007). Although the symptoms of diabetes secondary to chronic pancreatitis are the same as any other form, it does have distinct clinical characteristics. The most notable are wide fluctuations in plasma glucose levels and the tendency to unpredictable, frequent and severe hypoglycaemic episodes (Diem, 2002).

and they put me on a tablet and it just made me low (blood sugar) all the time and I got afraid of it and I stopped taking it and I didn't go back to anybody ... (Participant 7 – Interview 2)

Diem (2002) also argues that factors specific to chronic pancreatitis that contribute to this tendency include low carbohydrate intake, malabsorption/maldigestion, glucagon deficiency, increased intestinal transit, alcohol and non-compliance with diet and medical therapy. Given the unpredictability of disruption in chronic pancreatitis, it is difficult at times to control these factors. Furthermore, whilst a person may not intend to be non-compliant, the tangibility and immediacy of pain and gastrointestinal disturbances takes precedence over the less intrusive symptoms of hyper- or hypo-glycaemia thus precluding adherence to a recommended regime.

Overt physiological disruption attributable to diabetes was not a significant feature of the participants' experience at the time of the study. One participant was experiencing difficulties with her feet but its relationship to diabetes had not been confirmed.

Additional disruption to daily living centres mainly on balancing the need for hypoglycaemic control while meeting the dietary requirements associated with chronic pancreatitis but minimising pain and discomfort associated with eating certain foodstuffs. At times, participants feel that these contradict each other.

...when they tell you, you're a diabetic and you have to keep it (blood sugar) down to this ...and you're worried all the time about it

and I was walking too much...and then not eating as much as I should have... (Participant 2 – Interview 1)

like the diet for the diabetes and the diet for the hiatus hernia are actually clashing on me...so I'm caught between the two of them (Participant 6 – Interview 1)

Co-existing pathologies or co-morbidities exist for seven of the participants and they compound daily disruptions in one of two ways. Where the condition and its symptoms were clearly distinguishable from those of chronic pancreatitis, they constitute additional disruption. For example, one participant had a 'frozen' shoulder, which limited her mobility and was a further source of pain unrelated to chronic pancreatitis. In other instances, conditions that produce corresponding symptoms such as nausea, vomiting and fatigue create confusion or are attributed erroneously to chronic pancreatitis. Added to this is the difficulty they have discriminating between the effects of the various pharmacological treatments.

I was having a lot of nausea as well – there was a suspicion between us and the GP that it was more to do with my gynaecological end of things (Participant 7 – Interview 1)

what they found out was my thyroid was underactive. And so they put me on 'eltroxyn'...so literally since I started taking that the tiredness is not a factor (Participant 9 – Interview 2)

The daily disruptions experienced by the patients in this study correlate with the clinical features of chronic pancreatitis highlighted in the medical literature. Overall, this is not surprising given the plethora of literature on the inexorable progression and permanency of chronic pancreatitis (Steer et al., 1995; Mergener and Baillie, 1997; Talamini et al., 2001; Uomo, 2002; Mitchell et al., 2003; Otsuki, 2003; Strate et al., 2003; Tyler Stevens et al., 2004; Cavestro et al., 2005). However, the discourse of the participants differs fundamentally in respect of the perceived significance of these clinical features. Medical discourse uses pancreatic morphology as a primary

indicator, whilst for the participants in this study the tangibility and severity of the symptoms are judged against the level of impairment in their everyday living. This supports the view in recent quality of life studies that pancreatic morphology changes do not coincide with patients' subjective experiences nor are they significantly associated with any domain of health-related quality of life (Pezzilli et al., 2004; Wehler et al., 2004).

That the participants in this study have impaired physiological functioning as a feature of their daily living is evident. Furthermore, the reported physical descriptors correspond with those identified in other studies where their impact on health-related quality of life was evaluated (Pezzilli et al., 2004; Wehler et al., 2004; Fitzsimmons et al., 2005). The results indicated that for those living with chronic pancreatitis one of the most pronounced impairments is in the area of physical role functioning.

5.3.3 Escalating/Salient physiological disruption

In addition to daily disruptions, participants in this study continue to experience what are designated salient physiological disruptions. The term salient is used as these disruptions are perceived as striking and conspicuous in nature and are marked by escalating and/or intolerable noxious events.

For the participants, escalating pain often accompanied by severe vomiting are the cardinal features of salient physiological disruption. Although other features such as jaundice, diarrhoea and physical weakness are present in some instances, it is mainly uncontrolled pain and vomiting that marks the disruption as conspicuous. As with daily disruptions, the pattern, intensity and duration of salient disruptions vary.

Despite diagnosis and treatment, salient physiological disruption remains an intrusive feature of participants' living with chronic pancreatitis. Although it is recognised in the literature that acute attacks can be superimposed on chronic pancreatitis, its pathogenesis remains unclear and therefore, its incidence is unpredictable (Smith and Fawcett, 2006). Participants in this study found the uncertainty and unpredictability of acute episodes difficult as they could not identify a definitive pattern and the incidence varied from year to year without

apparent reason. Although there is a suggestion that the early compensatory phase of chronic pancreatitis is associated with recurrent attacks of abdominal pain (Otsuki, 2003), participants' understanding of the morphology of chronic pancreatitis precluded making inferences with their own illness trajectory. Furthermore, the participants define what constitutes salient physiological disruption for them, which may not always correspond with pathophysiological determinations of an acute episode. What they do understand, however, is the need to abstain from alcohol. This corresponds with the widely held view that continued alcohol consumption is linked with functional deterioration, poorer pain control and consequently, more frequent acute episodes (Gorelick and Robles-Diaz, 2002). As a result, eleven of the participants stated they no longer consumed alcohol. For these, recurrent salient disruptions are demoralising.

Despite the marked effect, hospitalisation was not a given during episodes of salient physiological disruption. This is due, in part, to a general reluctance to be hospitalised particularly in instances where participants believe the symptoms will settle or that they can cope.

your parents called an ambulance but you asked them to cancel it... you knew in the back of your mind that you could manage and you did not want to go to the hospital. You knew what the treatment would be – you could almost do it yourself and they would keep you in for one or two weeks fasting and on drips (Participant 5 – Interview 1 researcher's notes)

there's other times when I've had attacks and I didn't even go to hospital...actually even worked through it (Participant 14 – Interview 3)

Nonetheless, following diagnosis, hospitalisation remains common particularly when complications of chronic pancreatitis occur. The most common local complications of chronic pancreatitis are pancreatic pseudocysts that can cause further complications of pain, infection, fistula, rupture and intracystic haemorrhage (Andrén-Sandberg and Dervenis, 2004). Eight participants

reported experiencing intense pain and subsequent hospitalisations from the complications of their existing pseudocysts.

Hospitalisation is regarded as disruptive for a number of reasons. In the first instance, the number of admissions and the length of stays involved each time interfere significantly with everyday living and functioning.

I ended up going in eight times to hospital over two years...for the pancreas – acute pancreatitis (Participant 8 – Interview 1)

I've had about 20 anyway... they're the ones I was hospitalised with – I've had minor ones that I knew myself that I didn't need to go into hospital (Participant 14 – Interview 1)

This is magnified by the participants' perception that hospitalisation worsens physical debilitation thus necessitating considerable recovery time. In addition to the overall disruption, there are events that occur in hospital that constitute salient physiological disruption for participants. These were largely associated with conspicuous or striking experiences that disturbed their sense of physical well-being. Examples include sudden complications or deterioration in their condition, uncontrolled pain, invasive treatment regimes and a dysfunctional body.

I mean I wasn't unconscious in intensive care – I was awake but the wires were everywhere – I was out of my brains – awful – out of my brains - I could see people but that's all (Participant 2 – Interview 1)

I remember two nurses holding me down by the shoulders and my arms. One of them had a mask on my face and that kept filling up with blood when I was breathing. And the others were holding me down 'cause I was fighting it – the only reason I was really resisting was because it was causing me an awful lot of pain and the camera where I could feel it going around (Participant 5 – Interview 3)

I was very incontinent at times...sometimes in the night when I was on some sort of a drip...I felt awful after I had been incontinent but it was impossible to avoid (Participant 13 – Interview 1)

don't remember another thing about that Saturday or early Sunday ...three weeks and a day before I came around – I don't remember crashing now...it was like flicking a switch, one minute you were there and the next minute you were gone (Participant 14 – Interview 1)

Salient physiological disruptions represent profound assaults on the integrity of the participants. During these periods, their lives are most severely disrupted due to the escalation and intensification of the noxious symptoms of chronic pancreatitis. It is at these times that the most significant depreciation in weight and physical strength occur and are rarely restored thereafter.

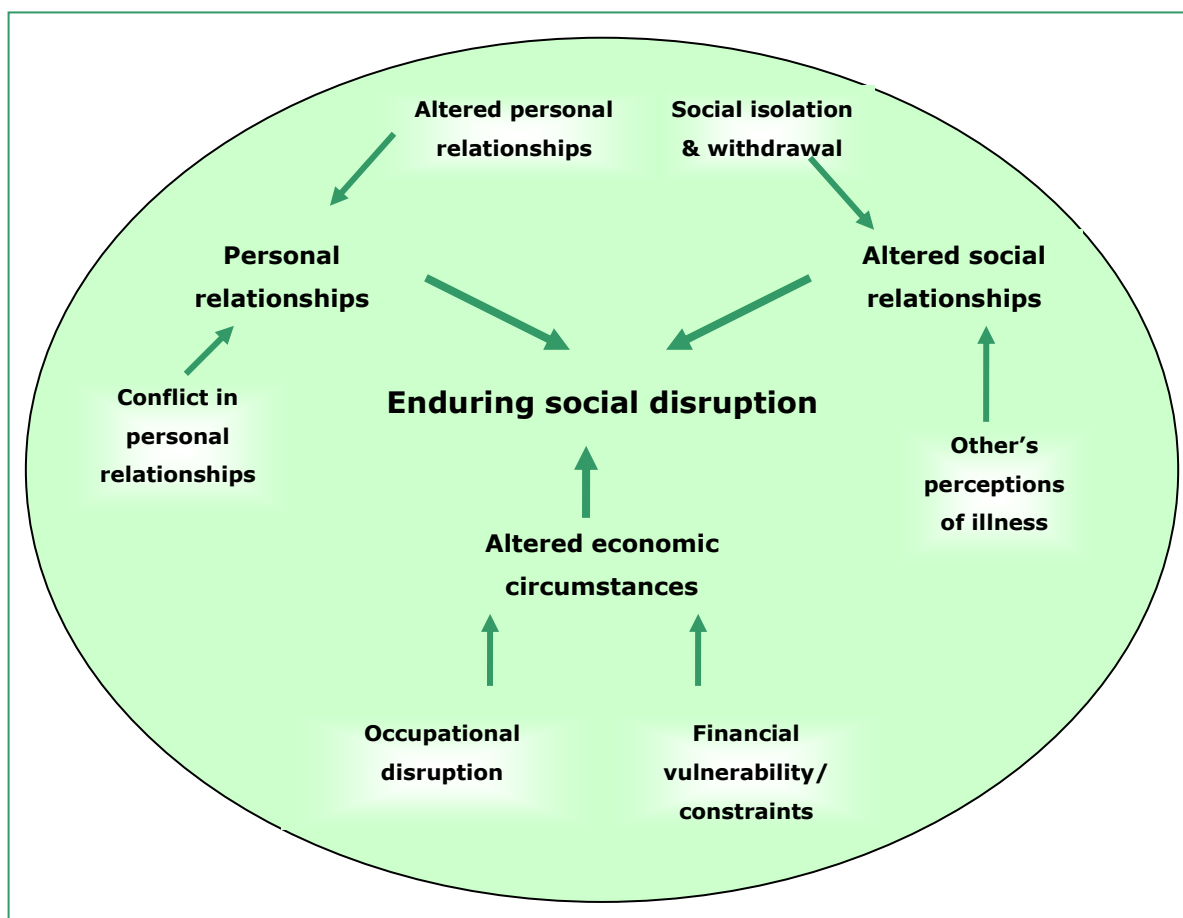
5.3.4 Summary

For the participants in this study enduring physiological disruption is described as unpredictable daily disruptions interspersed with episodes of escalating or salient physiological disruption. Daily disruptions are concerned with intrusive pain, interrupted sleep, inability to eat, gastrointestinal disturbances and food intolerance, incapacitating fatigue, loss of physical strength, iatrogenic effects and complicating and co-existing pathologies. Salient physiological disruptions vary in intensity and frequency but are marked generally by escalating pain and severe uncontrolled vomiting. Although disruption is an everyday feature of their lives, salient disruptions signify profound assault and it is during these times that participants are likely to feel the most severe decrement in their health. The unpredictable pattern of the symptoms in conjunction with the, sometimes, uncontrollable pain symbolises a threat to the integrity of the self. Chapman and Gavrin (1999) support such a view and suggest that persistent pain constitutes a disruption to one's psychosocial life trajectory. The disparity between the person one was and the person one is with chronic pain represents damage to one's integrity. The next section 'enduring social disruption' addresses the social impact of chronic pancreatitis on the lives of the participants.

5.4 Enduring social disruption

In this study, enduring social disruption encompasses the participants' perception of voluntary or enforced alterations to their social roles, obligations and functioning. Three themes that explicate enduring social disruption are 'personal relationships', 'altered social relationships', and 'altered economic circumstances'. 'Altered personal relationships' and 'conflict in personal relationships' are features that describe the social disruption in personal relationships. Within altered social relationships, the sub-themes include 'social isolation and withdrawal' and 'other's perceptions of illness'. Social and personal relationships are separated on the basis that the latter refers to the participants' immediate family. Altered economic circumstances are elucidated as 'financial vulnerability/constraints' and 'occupational disruption' (Figure 5.3). Assessment of the nature and extent of social disruption is founded on life before chronic pancreatitis.

Figure 5.3: Enduring Social Disruption



5.4.1 Personal Relationships

As stated above, the participants in this study distinguish between personal relationships and the wider social network of friends and acquaintances. Although such a distinction may appear obvious, they consider personal relationships most significant and most valued, both in terms of emotional support but also in respect of defining their social roles and discharging attendant responsibilities. Therefore, alterations to and conflict in these relationships are considered more disruptive than when they occur with friends and acquaintances. As stated by Gregory (2005), illness intrusion can mean considerable and sometimes permanent disruption to family life.

Differences in the make-up of the families in the study account to a large extent for the variations in identified priorities and values. This is particularly noticeable between married and single participants and between men and women where the emphasis on what is considered most disruptive varies.

Participants delineated their personal relationships as part of contextualising the impact of chronic pancreatitis. They outlined their family structure, their perceived roles and functions, their perception of the nature of the relationships and the significance of these relationships to their lives. In doing this, they are able to draw parallels between their social and personal life before and after receiving a diagnosis of chronic pancreatitis. The resulting disparity essentially forms the basis for determining the extent of the impact of the condition.

5.4.1.1 Altered personal relationships

All participants report changed personal relationships although for some the alteration is more stark than for others. Most perceive an alteration in the dynamic of their personal relationships. This seems to be based largely on their cultural and social beliefs and expectations of their role within the family. Role theory suggests that values, symbols and meanings of a culture become part of an individual's fabric as they develop socially, the product of which is delineation of role and role behaviour (Hodges et al., 2001). According to Gregory (2005) 'being family', embodies this complex, culturally-specific

knowledge and is acted out in the routine and everyday activities of family life.

When daily and salient physiological disruptions impact on the functional ability of the participants in this study, their roles as husband/wife, provider/worker, father/mother, and/or protector are compromised because they can no longer undertake the tasks that defined them in these roles. For example, one man feels it is his role to protect his wife and children but his condition sometimes limits his ability to do this – ‘when I was unconscious I wasn’t there to protect her’ (Participant 14 – Interview 3). Relinquishing roles and being ‘forced’ to adopt a ‘sick role’ threatens self-identity.

For those who are the main providers in the family, preserving this role and continuing to work is seen as most important in terms of sustaining their identity within the family. This was, sometimes, at the cost of other aspects of personal relationships such as sharing and engaging in social and recreational activities. Work comes first and maintaining that is exhausting (Charmaz, 1983).

by the time I get home someone asks me to go out, I make up all the excuses not to go... it suits me better to stay at home
(Participant 10 – Interview 1)

Furthermore, the perception that the financial burden of the family rests with them means they tend to continue to struggle to work sometimes at the expense of caring for themselves.

I’d rather suffer in pain, because I know she wouldn’t be able to cope with the kids without my financial support (Participant 12 – Interview 1)

For some of those who are no longer able to work the burden of financial responsibility has shifted to others in the family. For one man, it means his wife is now employed outside the home in order to supplement their income – ‘I can’t afford it, simple as that...my wife does a bit of home help’ (Participant

8 – Interview 1). For the single men living in the parental home, financial independence is difficult to achieve and the burden of supporting them has shifted back to parents.

Similar to the findings of Smith's (2003) study of the perceived family dynamics of 30 people with chronic pain, the women who are not employed outside the home consider maintaining family and home their most important roles. An inability to sustain these fully also means a shift in responsibility where their husbands now assume aspects of household maintenance not previously within their domain. Gulick's (1998) study also found that saving limited energy for most important roles such as employment, homemaking and personal care activities was a feature of daily living of people with multiple sclerosis.

One woman feels her relationship with her young son has been affected by her illness behaviour. Although she recognises that for the most part she is a 'good' mother, consistent with the findings of Wilson's (2007) study of mothers, periods of acute illness pose a threat to this identity. Furthermore, she is acutely conscious that her response to her illness is not conducive to her son's development. As a result she sometimes sees behavioural responses in the child, which she believes are a reflection of her own behaviour in illness.

most times he talks to me in a shout...I have seen some of the traits I don't like about myself coming out in him (Participant 7 – Interview 1)

That relationships with children alter as they learn and adapt to the presence of chronic illness is supported by several studies (Fitch et al., 1999; Smith and Friedemann, 1999; Smith, 2003; Söderberg et al., 2003). However, within these studies it was not possible to discern from the findings if there were any negative effects on the children. Snelling's (1990) review of the literature does suggest that pre-adolescent children of mothers with chronic pain may be more likely to experience negative emotional impact.

For those who spoke of sexual relationships, all indicated that the condition affected the nature and frequency of sexual activity. Some no longer had sex whilst others experienced intermittent periods where they felt unable due to the physical symptoms and pain – ‘it wouldn’t be as great now...anybody that’s sick it’s going to...’ (Family member – Wife) or because they felt their libido was affected by the condition and medication – ‘you lose your libido as well with this condition...I mean I wouldn’t really care if I never got it again in my whole life (Participant 7 – Interview 1).

The literature has highlighted that chronic illness and/or chronic pain impinges on sexual activity (MacDonald, 1988; Nusbaum et al., 2003) and was also referred to in Fitzsimmons et al’s (2005) quality of life study in chronic pancreatitis. However, there is a lack of consensus as to whether or not this is a contentious issue in marital relationships (MacDonald, 1988; Snelling, 1990; Snelling, 1994; Smith, 2003; Söderberg et al., 2003). In this study, the participants and their partners reported that it did not affect the overall strength of their relationship, which is consistent with the findings of Öhman and Söderberg’s (2004) study of 14 close relatives of people with serious chronic illness.

All except one participant identified members of their immediate family with whom they have a particularly close relationship. In illness, these family members are those who assume most responsibility in protecting, supporting and advocating for the participants and are also those in whom the participants confide.

even when I went over to visit the parents I couldn’t talk to them more than ten minutes because he needed my time, not them
(Family member – Sister)

In some respects, however, this represents a change in the dynamic of the relationship. Family and intimates closely monitor the participants’ health and illness behaviours. Primarily, they ‘watch’ for changes in their physical condition and monitor for signs of deterioration – ‘I could even see his eyes going yellow’ (Family member – Wife).

They constantly check how the participants are feeling. They tend to offer advice, opinions or reassurance regarding the appropriateness of their illness behaviours and assume some responsibility for ensuring the participants adhere to the recommended regimes.

went through the diet...everything I made for him was right. The only thing I wasn't giving him was oily fish (Family member – Wife)

Most participants feel their families 'worry' about them and it upsets them. One young man reported how difficult it is to 'watch' his family observe his suffering particularly when they become visibly distraught – 'I don't want to be seeing them when I'm in a really bad way as well' (Participant 5 – Interview 3). This was also a finding in Dewar and Morse's (1995) and Smith's (2003) qualitative studies where those with chronic illness (n=20 and n=25 respectively) are aware that it is distressing for family members to observe their pain or suffering.

Another highlighted how his wife is worried that should he have another severe attack he may not survive. Furthermore, both he and his wife are worried about the impact on their children. Although they are 'used' to his being hospitalised over the last eight years, the nature of his condition has never been discussed with the result that he is unsure of how they feel. Of his son, he says – 'just deals with it in his own way, doesn't mention it whatsoever' (Participant 14 – Interview 3).

That family become distressed and worry is corroborated by the five family members who participated in this study. Distress at the participants' physical condition and fear and worry about their continued survival threatens the family equilibrium. Like the female partners (n=14), of men with fibromyalgic pain in Paulson et al's (2003) study, the family members in this study feel the illness is at the forefront of their lives.

five years of just constantly worrying about him... he can't even eat, he can't sleep, he's not drinking – he doesn't have a girlfriend, he

doesn't have a job, he doesn't have a life full stop (Family member
– Sister)

Whilst most participants highlight that the ability to confide in their families is of central importance, paradoxically they tend to 'hide' worsening symptoms because of the worry they cause – 'I wouldn't unduly worry her... because I think she actually took it worse than I did' (Participant 14 – Interview 3). Not wishing to burden the family was a feature of Öhman et al's (2003) study of 10 people with various and serious chronic illnesses and is reflected in this study where participants speak of not wanting to burden their families emotionally. At times, therefore, they withdraw by refusing to discuss the condition or how they are feeling.

your parents would know when you were not well but you tended to withdraw and keep yourself to yourself (Participant 5 – Interview 1
researcher's notes)

In other instances participants 'hide' behaviours that are considered 'risky'. Risky behaviour is associated with non-adherence to prescribed regimes and particular to this study, consumption of alcohol. Where participants continued to drink alcohol, some did so surreptitiously because of the worry and conflict it causes in their personal relationships – 'she didn't know I was drinking' (Participant 12 – Interview 3).

Most participants and family members report restrictions in respect of family activities and holidays since being diagnosed with chronic pancreatitis. Consistent with the findings of other qualitative studies, restrictions are predicated on the physical well-being of the participants and life is not as spontaneous as before (Paulson et al., 2003; Baanders and Heijmans, 2007). The unpredictability of the pain precludes long-term planning and participants report, for example, feeling reluctant to travel abroad for fear of the onset of pain.

I've been afraid to go a few times...just in case you would get an attack – what would you do? (Participant 2 – Interview 1)

Several of the participants report a positive effect on the dynamic of their personal relationships. Some of the married couples remain 'as close as ever' (Family member – Wife) and many of the others highlight how their family unity has been strengthened by the experience – 'if anything it really brought us closer – none of us would even dream of having an argument now' (Family member – Sister). This is consistent with the finding of Eggenberger and Nelms' (2007) qualitative study, of eleven American families whose relatives had been hospitalised with a critical illness, that a loved one's suffering can have a profound and bonding effect on the family. In addition, Öhman and Söderberg's (2004) Swedish study of fourteen close relatives of those with serious chronic illness and Baanders and Heijmans's (2007) longitudinal study (n=1093) of partners of those with chronic physical disease in Holland, report intrinsic relationship rewards emanating from the realisation of having a good home and family. However, a finding in this study and consistent with those cited above is that reward factors co-exist with tension and conflict in personal relationships.

5.4.1.2 Conflict in personal relationships

In this study, not all participants speak of conflict in personal relationships but those who do are married. That is not to say that conflict is confined to married couples but the issue was not raised by participants who lived alone or with their parents.

A source of conflict for participants is 'being told what to do' and appears to arise from family concerns or beliefs about what exacerbates or worsens chronic pancreatitis. They offer advice about working, recreation, health promoting activities, adherence to prescribed regimes, management of symptoms and seeking professional help. Whilst participants acknowledge this advice is given in their best interests, they believe that others cannot understand what it is like to live with the condition. Similar to those in Penckofer et al's (2007) focus group study of 41 women with diabetes, at times they find such advice infuriating. Furthermore, they believe they know their own body best and as such are able to take appropriate action when necessary. In instances where the participant ignores or rejects advice conflict

can ensue. The daughter of one participant highlighted this when she said of her parents;

take more Creons with that cake...'No, I'm just going to take one'...and they just sit there and argue for a half an hour (Family member – Daughter)

Family members describe feelings of frustration, anger and fear that participants are not doing all they can to prevent their condition deteriorating. As found in other studies with family and close relatives, trying to remain patient is difficult (Söderberg et al., 2003; Richardson et al., 2007) particularly when they perceive the participant's pain through their body language – 'he can't lie down, because he has a pain, he's up, he's down, he's twisting, he's turning' (Family member – Wife). Participants' refusal to acknowledge or discuss it increases the potential for conflict.

it's desperate to look at somebody sick and in pain, chronic pain and there's not a damn thing you can do and then when you say something it's the wrong thing (Family member – Wife)

For the participants, balancing between the need to continue to function in their roles within the family and containing the physical symptoms of the condition is also a source of conflict. In these instances what the participants consider their priorities are often at odds with those of the family.

(daughter's name) would say 'you're going to be carried out of there in a box'...she'd see me as not looking after myself and of course she gets odd (Participant 4 – Interview 1)

In addition, if the participants forego help-seeking or limit analgesia, tension and worry within the family is further exacerbated. In these instances participants are seen as contributing to a worsening of their condition.

because of the way you are and how sick you are I still I think you're not doing yourself any favours (Family member – Wife)

Two of the male participants in this study report that alcohol consumption has caused or continues to cause conflict in their marital relationships. These men describe themselves as alcoholics and although both state the pattern of their alcohol consumption has altered and lessened, they are aware that they should abstain completely. Their inability to do so triggers conflict in their personal relationships – ‘I had a few pints...it would start an argument anyway (Participant 8 – Interview 3).

For one of the men the conflict escalates when his wife deems that he has been consuming alcohol surreptitiously. As a result, any deterioration in his condition is attributed to hidden alcohol abuse regardless of whether he has been doing so or not.

you have to understand her point of view because it’s not just me living with it – for all the stuff she’s put up with over the years and me drinking ...gone behind her back ...so I know she doesn’t trust me (Participant 12 – Interview 1)

Although he claims to understand his wife’s concerns, this man becomes angry when confronted with his alcohol consumption. This is in part due to feelings of guilt associated with the disruption he believes he is causing within the family but also because he claims his wife does not understand how difficult it is for him to stop drinking alcohol.

there’s no-one really else that understands – I don’t even remember the last time she had a drink but she doesn’t understand what’s in my head (Participant 12 – Interview 2)

Family concern for the welfare of both of these men appears to be overlaid with a sense that they are contributing to their own demise. This was also a finding in other studies of those with a range of chronic illnesses, where either past or continued behaviours generated feelings of anger (Charmaz, 1983; Rajaram, 1997; Lee and Poole, 2005). Salient physiological disruption heightens these emotions and causes additional strain on interaction between the participants and family members.

In several other studies of chronic pain (Snelling, 1994; Thomas and Johnson, 2000), multiple sclerosis (Robinson, 1988), end stage renal disease (Hagren et al., 2001) and fibromyalgia (Paulson et al., 2002), physical symptoms and bodily pain were found to lower participants' tolerance and cause inflated emotional reactions and unstable temper. Similar responses are reported by the participants in this study. Frustration, moodiness or anger occur and can be directed at family – 'I can control it pretty well in front of everybody except the people closest to me' (Participant 7 – Interview 1). Although family members attempt to tolerate and understand exaggerated reactions because of the presence of pain and physical symptoms, at times they too become angry and upset – 'I was on the verge of tears because he was so crotchety' (Family member – Wife).

These situations create tension in close relationships and result in strain in family members. In some instances anger responses from family members or participants creates a spiral of conflict.

I'm not happy...some nights when she comes she'd start moaning...after sitting on your own all day, your head is filled up with a load of stuff and you just say 'I'm going for a pint' (Participant 12 – Interview 2)

One woman feels that, at times, her mood swings and anger are extreme and disrupt any semblance of 'normal' family life. Realising that her son is alert to the family conflict only serves to exacerbate her sense of guilt.

Mammy, we'll have no fights now when we go in the house and no shouting because you're always shouting at Daddy (Participant 7 – Interview 1)

5.4.2 Altered Social Relationships

5.4.2.1 Social isolation and withdrawal

Social isolation and withdrawal is a feature of enduring social disruption and is present in the lives of all the participants in this study. However, there are

individual variations in the importance participants attach to social interaction and networking and in the perception of the impact of social isolation. For some, immediate and extended family networks are deemed sufficient to meet social interaction needs whereas for the younger participants and those who are single or who come from smaller families wider networks seem to be important.

Regardless of the constitutive nature of their social networks, daily physiological disruptions associated with intrusive pain, gastrointestinal disturbances and food intolerance and inability to eat limit participants' ability to take part in social activities. As one participant's mother said,

eating is such a chore for (participant's name) whereas for us eating is one of the pleasures of life (Family member – Mother)

For others, incapacitating fatigue affects their willingness to attend social gatherings, either because they want to conserve their energy or because their psychological and physical tolerance is lowered.

I'm not able for a crowd and I get a bit agitated... every little thing drains me (Participant 6 – Interview 1)

During times of escalating physiological disruption all participants feel compelled to withdraw from social interaction.

I do go to ground a bit...it's my way of dealing with it...the most mundane task becomes a chore when you are feeling that bad (Participant 1 – Interview 2)

While salient physiological disruptions are seen as legitimate reasons to cancel social engagements, doing so because of escalating daily disruptions tends to make participants feel uncomfortable. Although these patterns of disruption varied, participants describe feeling frustrated as if in a sense they are 'letting others down'.

I bore myself telling people – it's like a cracked record and I don't even want to start telling people I'm sick again (Participant 1 – Interview 2)

Consistent with the findings of this study, being forced to restrict social lives because of debilitating symptoms is a feature of many studies on various chronic illnesses (Charmaz, 1983; Kleinman, 1988; Fridfinnsdottir, 1997; Massé, 2000; Thomas and Johnson, 2000; Asbring, 2001; Hagren et al., 2001; Hodges et al., 2001; O'Neill and Morrow, 2001; Kralik, 2002; O'Neill, 2002; Öhman et al., 2003; Paulson et al., 2003; Jerlock et al., 2005; Lee and Poole, 2005; Fraser et al., 2006; Hensing et al., 2007; Lütze and Archenholtz, 2007). In respect of quality of life studies in chronic pancreatitis, Wehler et al (2003; 2004) and Pezzilli et al (2005) both determined that deterioration in social functioning was not clinically important. Overall, however, they found that patients with chronic pancreatitis had lower scores, than the general population, in all domains of the Medical Outcomes SF-36 instrument. This would imply that there is some social functioning impact as a consequence of the condition. This inference finds some support in Fitzsimmons et al's (2005) study where it was found, in the patient interview phase, that social isolation was a characteristic of living with chronic pancreatitis.

Although physical debilitation is a seemingly obvious reason for social withdrawal, it was not possible to determine from these chronic pancreatitis studies, whether or not other factors contributed to social withdrawal and isolation. In the general chronic illness literature cited above, secondary reasons for ongoing narrow or restricted social engagement were reported. These are associated mainly with factors that create a sense of being marginalised socially. Commonly cited issues within the context of social interaction such as 'visibility' or 'invisibility' of the condition, 'being discredited' by others and feelings of 'being different' are reflected, to some degree, in the findings of this study. However, a major intervening factor in how they are constituted is the role of alcohol in the social culture of Ireland.

The participants in this study, consider that their involvement in social engagement outside of work and family is marginal and for many this is

directly related to the fact that they no longer consume alcohol – ‘the fact that I don’t drink – people in Ireland think that’s weird’ (Participant 1 – Interview 2). One young man contributes his increased sense of isolation to the fact that he no longer drinks alcohol.

a friend you had for many years – when you told him you no longer drank you did not hear from him anymore (Participant 5 – Interview 1 researcher’s notes)

Because drinking alcohol is contraindicated in chronic pancreatitis, the participants feel ‘different’. Several stated that they feel they are on the periphery when they are in the company of those who are consuming alcohol. They no longer feel ‘part of the party’ (Participant 2 – Interview 1). Their sense of ‘being different’ and ‘not fitting in’ is intensified when friends or acquaintances become intoxicated.

it’s very hard for me to talk with people who are drinking...it’s generally how they perceive me...because they are now under the influence and find a lot of things funny...whereas I wouldn’t. And a lot of the time people would see you as a bit of a bore (Participant 4 – Interview 3)

When participants engage socially they are often questioned as to why they will not consume alcohol.

do you tell them why...or ‘ah, go on you’ll have a drink’...I might just say I’m driving...I might say I don’t drink...then they go ‘why don’t you drink’ and ‘oh I’ve kind of got a medical thing’ or do you say ‘I’ve got chronic pancreatitis’ and they say ‘what’s that?’ (Participant 1 – Interview 2)

In these situations, the general implication is that it is not normal to abstain from alcohol. One participant said it has been described by an acquaintance as a ‘life sentence’ (Participant 2 – Interview 1). Participants acknowledge that living with an unpredictable condition and abstaining from alcohol in

contemporary Ireland whilst attempting to maintain a meaningful social life is difficult. As a result, their level of engagement is not the same as it was prior to diagnosis with chronic pancreatitis. They control their involvement in social gatherings by choosing carefully those they attend or they limit their attendance to short periods.

if it was someone I knew real well and it was a party, I'd go, give a card, half an hour and then I'd be out (Participant 2 – Interview 1)

Others tend to confine their networking to those with whom they feel safe and who are supportive in facilitating their abstention from alcohol.

I tend to go into social situations with people who know my situation...in some ways I hand accountability for looking after me to someone else (Participant 3 – Interview 3)

For some participants, social interaction prior to the onset of chronic pancreatitis centred on the public house. One man stated it provided the interaction he was missing because he lived alone whereas others described it as a way of life. Now they do not know what else to do.

I have no hobbies, they took my hobby off me...it's a terrible changeover from one extreme to the other (Participant 8 – Interview 2)

Their friends are all drinkers and any social activity always involves alcohol.

they go out for a game of pitch and putt alright but afterwards it's straight into the pub. I know it's wrong to avoid them – I should be stronger and just turn around and say, 'look I don't want to drink, I suffer with pancreatitis' (Participant 12 – Interview 2)

However, knowing that continued alcohol consumption is implicated in the escalation or worsening of physiological assault they try to distance themselves – 'I don't socialise in pubs – I haven't seen the inside of a pub in

over two years' (Participant 13 – Interview 1). This is because they do not trust themselves to abstain from alcohol or they feel pressured by their friends or family to drink.

my sister (name) when she gets a few drinks into her, 'I'll get a pint for you and don't tell anybody'. Once it's offered to you – they know about the pancreatitis...they don't understand if you push so hard (Participant 12 – Interview 2)

As a consequence they feel socially isolated but are steadfast in their view that they find it extremely difficult to consume non-alcoholic drinks in a pub. Part of this appears to be associated with the perception of their image as 'drinker' and being seen with a non-alcoholic drink draws attention or comment.

These participants continually vacillate between wanting and not wanting to drink. The social isolation they perceive causes them to feel 'unhappy' or 'lonely' and in one case has prompted the participant to question the purpose of his living. In turn, these emotional states lead to an increased desire to drink alcohol despite the consequences.

when I saw him, how desperate he looked the other night, 'oh f***, I don't want to be like that'. But then that's only saying that, that night...tomorrow if I choose to drink, I'd say I will 'f*** it, if I'm going to end up like S, I'll end up like S' (Participant 12 – Interview 2)

Continuing to drink alcohol despite negative physical or psychological problems supports these participants' description of themselves as 'alcoholics' (Ting-Kai et al., 2007). While the severity of their alcohol dependence was not explored in this study, it is undoubtedly a mediating variable in its continued consumption. However, the context of their alcohol consumption is always social gatherings, therefore it is suggested that the psychophysiological need for alcohol together with a desire to be a part of their peer group and not

wanting to be identified as 'different' may account for what can be described as hazardous or risky behaviour.

Support for alcohol abstinence or alcohol consumption as a secondary reason for social withdrawal and subsequent social isolation could not be found in the literature. However, there are some parallels with the patterns of behaviour in respect of food restrictions in studies of people with coeliac disease (Gregory, 2005) and diabetes (Charmaz, 1983; Rajaram, 1997). In these studies participants and family members describe how wanting to project a 'healthy' or 'normal' image socially resulted in risky dietary choices in social situations.

In addition to studies citing social withdrawal and social isolation from the perspective of people with chronic illness, some address the social restrictions on family members (Anderson, 1988; Rajaram, 1997; Söderberg et al., 2003; Öhman and Söderberg, 2004; Gregory, 2005; Eriksson and Svedlund, 2006; Baanders and Heijmans, 2007; Richardson et al., 2007). These studies report various limitations on the social relations of the partner because of the social impairments of the person with the illness. This may account for why, apart from intermittent disruption, family members' social lives in this study are not significantly limited as the participants, despite some compromised functioning, remain independent in many activities of living.

5.4.2.2 'Others' perception of illness'

Others' perception of illness is concerned with the 'lay' view of chronic pancreatitis and by association those living with it. Others are defined as those in the participants' immediate and wider social or work context. Issues of concern are how others' perceptions of the legitimacy of the condition are markers for participants' assessment of being validated in their sick role. Although this seems to contradict the desire, expressed earlier, to be seen as 'normal', it is associated with being able to enter the sick role rightfully when necessary thereby having their illness experience recognised and being exempted from role responsibilities and social obligations.

For the participants in this study, the reality is that chronic pancreatitis is 'hidden' on two levels. Primarily, the condition is unknown in the wider social

context and secondly, overt physical disability is generally not evident. These are key factors in determining the legitimacy of the condition – ‘chronic pancreatitis – people have no understanding of what the illness is’ (Participant 1 – Interview 1). As a result, participants feel they have to explain its nature and implications since its impact is not immediately evident.

you’ll know if I’m having an acute attack but apart from that it’s pretty hard to tell (Participant 1 – Interview 1)

Having to explain causes a dilemma about ‘how much’ information to disclose. Ultimately, the decision is predicated on whether or not disclosure is necessary and on the participants’ perception of whether those they are telling ‘care’ or are ‘interested’ in knowing about the condition and its effects.

Necessary disclosure is concerned mainly with occupational contexts or institutions such as insurance companies. Even then, however, levels of disclosure vary. For example, one young man disclosed to his university, his difficulties in the pre-diagnosis phase so that he could defer his academic course for one year. At another level, a participant is selective with the information he discloses to his employers because any association with an alcohol-induced illness has, in his view, implications for his employment – ‘if they found out I was back on the drink, they’d f***ing sack me’ (Participant 12 – Interview 3).

For some participants others’ perceptions concern them as they do not want to be seen as malingerers.

it became very important to not be seen to be taking the piss...I didn't want people to think, that I was the type of person that would take advantage of that situation (Participant 4 – Interview 2)

This young man’s worry reflected that of others in respect of their employment with the result that even in times of physiological disruption they continue to strive to meet their obligations – ‘I always try and work through (Participant 10 – Interview 1).

Participants also identify communicating with state or other institutions as necessary disclosure but highlight that, on occasion, it is detrimental to their lives.

if you apply for a mortgage and you put down you've CP you're not going to get it...I discussed it straight up and was looking for life insurance...they said 'no way' and that was a number of banks and building societies (Participant 1 – Interview 1)

Several of the participants highlight that they rarely confide in others or voluntarily disclose information about their illness experience. Some attribute this to the complexity of the condition – 'it takes too long... it's not that I had a heart attack' (Participant 6 – Interview 1) whilst others believe – 'you have an unseen illness that nobody knows about...sure who wants to hear about it?' (Participant 3 – Interview 2). However, the primary marker is the perceived response of those with whom they are talking and the importance of the relationship.

Participants report reactions that range on a continuum from 'blasé' (Participant 4 – Interview 2) to 'I know someone who had that...oh, they died' (Participant 3 – Interview 2). Responses that are confirming reinforce the credibility of the illness experience of the participants. Depending on the reaction, participants judge whether further disclosure is acceptable or appropriate. Nonetheless, no matter how validating the reactions or how important the relationship, participants identify rules of social engagement where unspoken boundaries about disclosure exist. Whilst they may want to 'tell' enough to garner a sympathetic response, too much information may lead to alienation – 'if you start mentioning the word pain to people it makes them uncomfortable' (Participant 1 – Interview 1).

Participants consider negative reactions to be those where others appear to believe they are exaggerating the impact of the condition or where their disclosures are not taken seriously. For one man, prior to his condition being given a name, his friend – 'thought it was psychosomatic' (Participant 4 –

Interview 1). Others report being questioned continuously as to whether or not they are abstaining from alcohol.

if I get a bout of pancreatitis, I've a hell of a job convincing other people that I haven't been drinking (Participant 3 – Interview 3)

Another participant's wife speaks of how a friend will not accept that he cannot drink alcohol and continues to bring it to the house.

he knows he's been in hospital twice and he knows that if he drinks again he'll end up back in hospital and he still does it (Family member – Wife)

Although the participants in this study proclaim immediate family to be most important in terms of social relationships, it is evident, from the findings outlined above, that others' perceptions matter and are a factor in altered social relationships. These findings are reflected in the literature of studies of people living with various chronic illnesses where positive social support can have a protective effect (Ciambone, 2001; O'Neill, 2002) while negative reactions to the presence of illness can be discrediting and devaluing (Charmaz, 1983; Dewar and Morse, 1995; Hörnsten et al., 2004). Negative reactions are linked with social withdrawal and isolation.

Several studies report that negative responses in the form of unsolicited comments (Charmaz, 1983; Penckofer et al., 2007), lack of insight and understanding (Dewar and Morse, 1995; Öhman et al., 2003; Lee and Poole, 2005; Beal and Stuijbergen, 2007) not wanting to hear about symptoms and pejorative views of experiences (Thomas and Johnson, 2000) constitute an attack on self-identity and are discrediting and devaluing.

These reactions reinforce the individual's sense of being different (Kralik, 2002) and compromise their sense of belonging. Belonging involves ideas about prevailing values and to some extent determination of an individual's worth within the group. Chronic illness challenges worth and continued credibility as a functioning person within society. Others' perceptions can

accentuate these feelings and create a sense of being re-valued by the world (Lundman and Jansson, 2007) and found wanting.

As indicated previously, social withdrawal is one strategy that those with chronic conditions adopt in order to protect their self-worth. However, in conditions such as chronic pancreatitis, which have low social visibility, it is also possible to maintain an outward sense of 'normal'. Corresponding with the findings of this study, others have found that selective or non-disclosure of the existence or impact of the condition and continuing previous habits and life-style patterns are ways in which normality can be maintained (Charmaz, 1983; Hodges et al., 2001; Joachim and Acorn, 2003; Hörnsten et al., 2004). In this way, the sense of 'being different' is minimised and sense of belonging is preserved thereby providing secondary validation of continued worthiness.

Selective and non-disclosure of information was carefully planned by the 13 women with scleroderma in Joachim and Acorn's (2003) study. As in the current study, this suggests that assessment of potential responses from others is undertaken prior to disclosure. Having few visible or external signs challenges others' acceptance of the existence and the impact of the illness (Hörnsten et al., 2004) and may be a factor in discrediting or devaluing (Charmaz, 1983; Dewar and Morse, 1995; Hörnsten et al., 2004).

This study and those cited above are consistent in that, where possible, disclosure is confined to those who are deemed to be supportive. There is some suggestion in the literature that social support can have a 'buffering' effect during stress conditions or even promotes well-being in and of itself (Hagerty and Williams, 1999). Therefore, although the participants in this study do not want to be viewed as other than 'normal', it is important that on occasion when they cannot perform in their normal social roles that surrendering those roles is recognised as legitimate. Others who are most likely to view them as credible, with a legitimate condition, are those to whom they disclose.

Maintaining previous life-style and habits as a way of sustaining normality involves, for some of the participants in this study, risk-laden behaviour such

as consumption of alcohol. This suggests that the need to belong sometimes over-rides the need to maintain physical well-being. Although little support for this contention could be located, Rajaram's (1997) study of those with diabetes (n=23) highlights risk-taking with food as a normalising factor.

5.4.3 Altered economic circumstances

Altered economic circumstances refer to the fiscal elements of 'economic constraints' and 'financial vulnerability' arising from living with chronic pancreatitis. Given the diversity of participants, there are variations as to what constitutes altered economic circumstances. However, a central issue in determining the significance for enduring social disruption is bound in the level and extent of 'occupational disruption'. Nonetheless, it is important to note that economic constraints and financial vulnerability also arise independently of occupational status and represent additional strain on family resources and future financial security.

5.4.3.1 Occupational Disruption

At the time of onset of chronic pancreatitis, ten of the participants were employed in some capacity (part-time, full-time, self-employed), one was unemployed, two were not employed outside the home and one was a student. At the time of the study, five of those previously employed were in receipt of disability benefit and considered unable to work. However, two of these hoped that some form of suitable employment would be a possibility in the future. Four were in full-time employment whilst one was part-time but progressing to full-time. The student had deferred his university course for one year. Of the two women who were not employed outside the home, one had never done so whilst the other considered it would not be possible to return to employment given the intrusion of the illness. The final person was in the process of seeking employment but issues related to her status prior to the onset of chronic pancreatitis were the main factors to be resolved before she could return to her previous occupation.

Although all participants experience interruptions in their working lives due to hospitalisation and unpredictable symptoms of daily disruptions, the scale and

level of disruption varies notably from person to person. A mediating factor that ultimately determines the permanency of occupational disruption is the nature of their work. Loss of physical strength, fatigue and the intrusiveness of pain are implicated in the ability to continue to work and is a major issue for those in manual occupations.

I was an upholsterer...I haven't done any since I got sick...I don't have the strength to pull the cloth (Participant 2 – Interview 1)

These findings correspond with those of other studies, which identify that physical limitations in terms of ability and the type of work are implicated in the extent of occupational disruption (Morgan, 1988; Lowton and Gabe, 2003; Lee and Poole, 2005). Lindholm et al (2002a) identified that manual workers with chronic illness have a statistically significantly higher risk of economic inactivity than those in non-manual occupations.

In addition, this study identifies that the unpredictable nature of chronic pancreatitis means that the participants are often unable to be flexible or respond to demands at short notice. For one man, this inability necessitated the closure of his company but was also a factor in why he was unable to find related work within his field.

I've applied for part-time work in the past year or two because I've wound down the business and I wouldn't mind something maybe 20 hours a week where they'd be reasonably flexible...but once you tell people, you basically get nowhere (Participant 1 – Interview 1)

This excerpt suggests that those with chronic pancreatitis are more likely to experience difficulties securing employment because of its unpredictability, particularly in terms of symptoms. Although support for this contention could not be found in relation to the condition, previous health related quality of life studies (Wehler et al., 2003; Pezzilli et al., 2004; Wehler et al., 2004; Fitzsimmons et al., 2005) report that a significant percentage of those with chronic pancreatitis are unemployed or retire early. Whilst this is important in terms of social consequences, by virtue of using quality of life measurement

tools, variations between occupational categories and constraints in securing employment are not explicated. However, some studies have been undertaken in the United Kingdom (Burström et al., 2000), Netherlands (Baanders et al., 2002) and Sweden (Lindholm et al., 2002a), which suggest that those with chronic illness have more problems securing employment than those in the general population and those who work in manual occupations are more liable to be unemployed. Furthermore, Calsbeek et al (2006) found that among 622 young people with chronic digestive disorders, some disease characteristics or symptoms are associated with more disease burden and are therefore an important determinant for employment.

Although being unable to work occurred across the life-stages, for the individuals in this study, it is an overt representation of the impact of the illness because it symbolises that they can no longer function as they would wish in one of the most fundamental social roles, that of 'worker'. Being unable to work is evidence of their 'being different' and clearly signifies to them that they are not 'normal'. Being a worker is part of an individual's self-identity and according to Boeije et al (2002) being unable to do so constitutes being stripped of a salient concept of life and attendant loss of value.

Working is one means by which people manifest their sense of belonging and being separated from colleagues marginalises the individual and intensifies the feeling of being socially isolated (Nätterlund et al., 2001). Although the participants in this study did not refer directly to social isolation as a result of loss of work, they did so indirectly when referring to - 'loneliness' (Participant 13 - Diary entry), and 'everyday being the same' (Participants 2 & 8). As in Lundman and Jansson's (2007) study, work gives purpose and structure to these participants' lives. As indicated by one woman - 'I do need to go back to work...first of all for sanity' (Participant 11 - Interview 1).

For the younger participants, permanent occupational disruption also represents a loss of social potential. The possibility of achieving financial independence is minimal. Owning their own home is largely excluded, as being in receipt of disability benefit means they cannot apply for a mortgage.

Therefore, possibilities for achieving their desired social standing are limited and in some cases unachievable.

I wouldn't be in a financial position to have a family at the moment unless things picked up enormously (Participant 1 – Interview 2)

For those who continue to work, the possibility that they may not be able to do so at some time in the future is a concern. In keeping with those who were no longer working, disquiet centres on loss of social identity and feelings of worth associated with being a worker.

it's all to do with pride, going out and making a living and making your own way in the world (Participant 10 – Interview 2)

For another participant, the need to continue working is associated with his conception of having a reasonable quality of life. For him, depending on social welfare payments represents a loss of a sense of worth.

it's all very well to come out and know I have my medical card but I have no f***ing life to go with it...I have to feel that I have a sense of worth...to me it's no good having all my medication if I have to lie in a gutter in the street...what choice is that? (Participant 3 – Interview 1)

Many participants speak of financial security associated with working. Loss of potential earnings or anticipation of loss of earnings brings with it apprehension about meeting current or future financial obligations but also concerns about financial security for themselves and, where applicable, their families.

if I borrowed money – I've always had a fear that I wouldn't be able to pay it back. That's why work is very important as well (Participant 10 – Interview 2)

There is little doubt from the findings of this study that occupational disruption is implicated in adverse social consequences of chronic pancreatitis. Furthermore, it is likely that the disruption is also a factor in the increased risk of financial difficulties.

5.4.3.2 Financial vulnerability/constraints

Many of the participants outline how living with chronic pancreatitis has rendered their financial position more precarious. While actual and potential occupational disruption is a major factor in their assessment of their financial position, even those who did not contribute to the family income prior to diagnosis with chronic pancreatitis identify financial consequences. Financial vulnerability and constraints are implicated in enforced social isolation and withdrawal where participants and families no longer have the means to engage in social activity. Thus, financial status is a factor in the participants' social disruption.

For those who are no longer employed and living on disability benefit there is an acute awareness of the constraints of living on the allowance – 'I get disability allowance...I'd survive...just about' (Participant 2 – Interview 1). The notion of survival is evident in each of these participants' stories, where essential financial demands are met but additional 'extras' such as social outings, holidays and hobbies are excluded simply because they cannot afford them.

For those who continue to work or who are dependent on their spouse, ensuring that financial obligations are met becomes more difficult given the unpredictable illness trajectory of chronic pancreatitis. For some, the additional costs associated with prescribed medication and potential loss of earnings during periods of sickness and hospitalisation puts additional strain on the family finances.

we had a couple of bob in the bank there last year, and when I see the way it's eaten it up (Participant 6 – Interview 1)

One man considers that his financial situation is extremely vulnerable because disability or sickness benefit would render him unable to sustain his mortgage payments or care for his wife and children. This puts strain on family relationships as he continues to try to work even though he is experiencing frequent acute episodes but refuses to seek help.

I have to pay 460 quid a week – I get paid 550/560 quid a week and I have to pay that to make sure I don't miss my mortgage payments...that's why I don't want to go back to hospital (Participant 12 – Interview 1)

A factor for participants who work, who are self-employed or do not have the requisite social welfare credits, is that chronic pancreatitis does not appear on the list of prescribed illnesses or disabilities, which would entitle them to free medication (Citizens Information, 2007). Therefore, those who do not have a medical card must pay €90 per month for prescribed medication. Some state that existing financial demands are such that they cannot afford this additional outlay. For one man this meant that at times he did not have the money for his medication – 'I can't afford to be ill – I've no medication now' (Participant 3 – Interview 1).

The perceived or actual sense of financial vulnerability is reinforced by the participants' claims that they are unable to obtain life insurance – 'since I've been diagnosed no-one will insure me' (Participant 3 – Interview 1). Therefore, those who do not have a pre-existing policy are unable to obtain a new one. Consequently, those who may have been able to apply for a mortgage because they are still working are excluded because life insurance is a compulsory component of house buying.

However, being able to purchase a house is not the only reason why participants want to be insured. For one participant, inability to obtain life insurance distresses him because the cost of his death would have to be borne by his family – 'I don't have enough money for a funeral (Participant 3 – Interview 1).

For another man who has a life insurance policy, there is a concern that on his death, the insurance money may not be forthcoming. This issue came to the fore when, following a lengthy hospitalisation he made a claim on his mortgage protection insurance. When payment was refused, he became concerned about his life insurance policy

if I had have died – would the life insurance refuse to pay out? And that would leave (wife's name) in a mess (Participant 14 – Interview 3)

What is evident from these participants' dialogue is that concerns are often focused on the impact on family members and dependents rather than on themselves. This reflects the previously identified importance participants attach to their social roles and obligations and the resultant strain when they feel unable to discharge them.

That financial vulnerability and constraints are a negative social consequence of being diagnosed with chronic pancreatitis is not surprising given the unpredictable and sometimes profound physiological assault associated with the illness. However, a factor that was not raised in this study and may have implications for financial consequences is socioeconomic status. In Britain, it was found that it was an important factor in susceptibility to social consequences in long-term illness while in Sweden it is much less so (Burström et al., 2000). Although it is not possible to make any inferences in respect of the Irish system, there is an argument that social and economic consequences are dependent on social and labour market policies and employment protection (Lindholm et al., 2002a). Ideally therefore, those with chronic illness who are seeking employment or those who are rendered unable to work should not experience financial decrement. As indicated in this study, however, participants report that in practice there are areas where they perceive they are financially compromised.

5.4.4 Summary

For the participants in this study, enduring social disruption as a consequence of living with chronic pancreatitis is manifested through alterations in

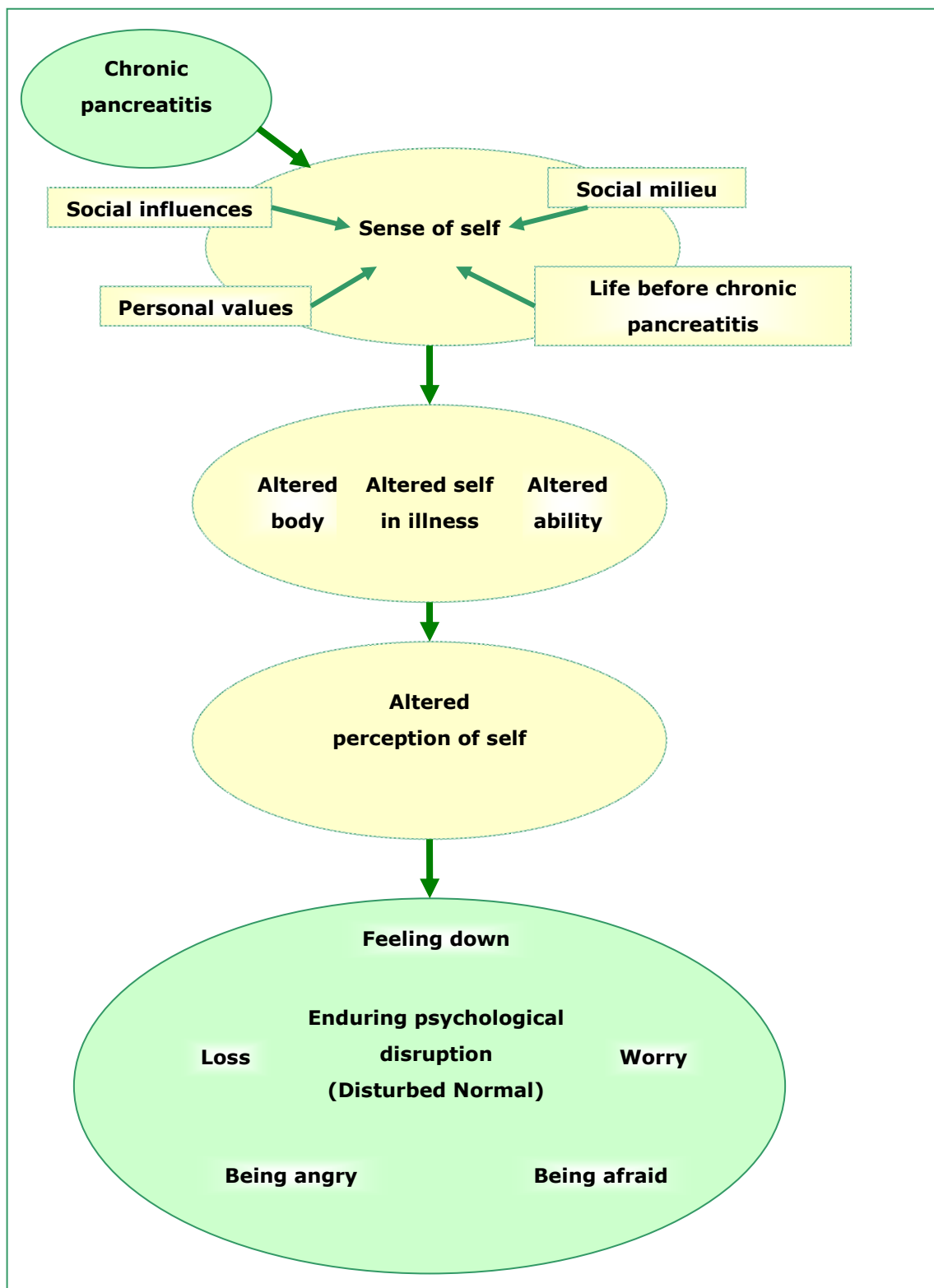
personal, social and economic circumstances. It is the interplay of these factors for each individual in their context and environment that determines their impact and the perceived level of social disruption. Furthermore, enduring social disruption is inextricably linked to enduring physiological disruption since the former can be said to be the social manifestation of the latter. Thus, threats to the integrity of the self arising from enduring physiological disruption are compounded by compromised functioning in social role performance. Although this suggests an asymmetrical relationship (i.e. one-way) between enduring social disruption and enduring physiological disruption it has been proposed by Lindholm et al (2002a) that adverse social consequences of chronic illness are detrimental to health, thereby implying a symmetrical relationship. Moreover, it is argued that the relationship between enduring social disruption and enduring physiological disruption are essential elements in the emergence of enduring psychological disruption, which is the focus of the next section.

5.5 Enduring psychological disruption – Disturbed Normal

In this study, enduring psychological disruption is rooted in the participants' discernment of an altered self in illness, a sense of being different to the person they perceived they were before being diagnosed with chronic pancreatitis. This difference is signified as disturbance in their cognitive and affective sense of normal. The sense of 'disturbed normal', which is the overarching theme, is predicated on who they perceived they were before their illness, which was situated in their sense of self (defining 'me'), their personal values, their social milieu, social influences and life before chronic pancreatitis. Largely, the measure of the disparity was verbalised by elucidating their perception of their altered body and altered abilities. Altered body results in an altered perception of self, which generates a series of emotional responses to their situation. 'Disturbed normal', therefore, is described largely in terms of mood and feelings and incorporates the sub-themes of 'being afraid', 'being angry', 'feeling down', 'loss' and 'worry' (Figure 5.4).

For the participants, the physiological assault of chronic pancreatitis was the precursor of disturbed normal. Impairment due to physiological disruption renders it difficult or even impossible to sustain their previous lives but, equally importantly, poses questions as to their future functioning. In physiological assault the body 'loses its silence' (Öhman et al., 2003) and the taken-for-granted assumptions about a smoothly functioning body are challenged (Bury, 1982; Kleinman, 1988; Charmaz, 1995; Williams, 2000). Thus, the integrity of body and self is destabilised leading to an altered self-concept. Being ill is not normal and similar to Kralik's (2002) study, self-esteem is eroded 'I'm a chronically ill 27 year old who's not able' (Participant 5 – Interview 2). Within each individual context, the disparity between who they were and who they are now signifies the impact of chronic pancreatitis for the participants in this study - 'I'll put it this way – I'm not the same fella she married' (Participant 8 – Interview 3).

Figure 5.4: Manifestation of enduring psychological disruption



5.5.1 Being afraid

Fear is a psychological consequence of physiological assault (Hensing et al., 2007) and is related to the primary stress appraisal of threat (Lazarus and Folkman, 1984). Threat is concerned with anticipated losses or harm that have not yet taken place but in the presence of stressors such as physical assault, impairment or disability, as identified by the participants in this study, psychological reactions occur, one of which can be fear.

In this study, the focus of the participants' articulation is on the affective or cognitive dimension of 'being afraid' that encompasses a range of discrete yet interrelated fears. The most prevalent are those related to the pain and complications of chronic pancreatitis, and fears associated with an unknown and uncertain future.

What is important here is that the fears identified by the participants are located in identifiable sources of threat to the well-being and comfort of their physical selves. Thus the explication of their fears is in keeping with the argument that it is a non pathological and normal primary emotion in the face of illness (Izard, 1991; Heikkilä et al., 1998; Bowman, 2001; Bowman et al., 2006). Bowman (2001) hypothesises that reactions such as fear come from a defensive self-protection associated with a healthy survival response.

For the participants, fear as an emotional response occurs on two levels. They not only fear the symptoms themselves but also have superimposed fears related to the significance of symptom occurrence. Primarily, they fear the escalation of pain or other noxious stimuli to a level where they perceive they are no longer able to tolerate them. In this instance, fear arousal is linked with secondary stress appraisal where self-efficacy in coping with the known stressors is determined. Perceived inefficacy is likely to result in heightened anticipatory and/or performance fears (Lazarus and Folkman, 1984). In this study, fears are compounded by remembered acute episodes and unrelieved, unrelenting and unpredictable physiological disruptions.

I've probably been the most scared...if this gets worse by any degree...'How am I going to deal with the pain? (Participant 4 – Interview 3)

Associated with their perceived tolerance levels of physiological assaults is the fear of hospitalisation. All participants fear hospitalisation because of its association with unpleasant and sometimes intolerable treatment regimes but more significantly, as a cogent indicator of deterioration in their overall condition.

the frightening thing now is, say...it turned into a bad pancreatitis episode, the thoughts of going back in (Participant 11 – Interview 1)

Over-arching the fears of noxious stimuli and hospitalisation is the perceived threat to the participants' overall integrity and future survival. For some, the fear is that the future will be no better than the present – 'what I can't face up to...is this as good as I'm going to get?' (Participant 6 – Interview 1). Long-term goals and hopes for a future are called into question.

sometimes I can't see us going around on our zimmer frames together at 80 (Family member – Wife)

Escalation of physiological symptoms and hospitalisation are linked with the possibility of dying.

I know probably the next bad dose could kill me...that's a fear I have (Participant 6 – Interview 1)

Fear of dying is uppermost in the participants' minds and is associated with the perception that their dying will be traumatic.

I have no problem with death it's the transition – the pain and suffering that goes with it (Participant 3 – Interview 1)

These fears are compounded by an uncertain and largely unknown illness trajectory, a lack of surety regarding treatment and the poor long-term prognosis of chronic pancreatitis. Furthermore, given the age profile of the participants (26-58) being confronted with the possibility of their own death was also fearful.

I know everyone's going to die eventually but you just don't think that – you have more or less control over your own death in a way
(Participant 12 – Interview 2)

Within the literature, there is some support for the findings that symptom or treatment severity accounts for fear arousal (Moore Schaefer, 1997; Heikkilä et al., 1998; Thomas and Johnson, 2000; Ciambone, 2001; Jerlock et al., 2005; Hensing et al., 2007). These are mainly inductive qualitative studies undertaken from a patient perspective and confined to acute or chronic conditions where symptoms are known to be noxious; for example, rheumatoid arthritis, neuropathic pain or unexplained chest pain.

Considerable support is found in the literature in respect of fears that threaten overall integrity and future survival. These studies address a wide range of conditions both acute and chronic from pre-diagnosis to end-stage. In all, the identified fears are located in the significance or meaning attached to the symptoms or progression of the condition. These include, fear of disability and increasing dependence (Charmaz, 1983; Rogers, 1997; Lütze and Archenholtz, 2007), fear of multiple losses (Sullivan et al., 2003), fear of worsening symptoms (Massé, 2000; Woodcock and Kinmonth, 2001; Joachim and Acorn, 2003; McCormick et al., 2006), fear of recurrence (Moore et al., 2004) fear of the unknown (Fridfinnsdottir, 1997) and fear of dying and death (Kleinman, 1988; Charmaz, 1991; Ciambone, 2001; Hagren et al., 2001; Öhman et al., 2003; Sullivan et al., 2003; Andenæs et al., 2004; Jerlock et al., 2005).

Moreover, these studies corroborate the finding that fear does not occur in isolation but is a part of a complex psychological response to illness that includes a range of other primary and secondary emotions. For example,

Izard (1991) contends that fear is experienced as a sense of insecurity, uncertainty and loss of control all of which were features of the losses experienced by the participants in this study.

5.5.2 Loss

According to Robinson and McKenna (1998), characteristics of loss include; being deprived of someone or something that one had or ought to have sometime in the future; that which has been taken away was valuable and the meaning of the loss is subjectively determined by the person experiencing it. Consistent with seminal work on chronic illness, the participants in this study experience multiple losses (Bury, 1982; Charmaz, 1983; Kleinman, 1988; Charmaz, 1991). For them, the cumulative effect of physiological assault and tangible physical and social losses (loss of functioning, loss of social roles) manifests in symbolic psychological losses (loss of confidence, coherence, control, healthy self). This is commensurate with the view that loss does not occur in a vacuum but that one loss often precipitates others (Robinson and McKenna, 1998). It is these psychological losses that are the focus of this section since they reflect the meaning and significance of physical and social losses for the participants' concept of self.

5.5.2.1 Loss of healthy self

Loss of healthy self is judged primarily by the perceived degree of physical debilitation (strength/stamina/fatigue) and alteration to their structural selves (weight loss/cachexia) – 'I was all shoulders...I always had muscle' (Participant 2 – Interview 1). Confirmation from others of their changed physical ability reinforces their loss with a resultant alteration to their image of self.

gone from being a very strong, physically strong, heavy man...you could ask him to do anything...I don't like asking him to do anything now (Family member - Wife)

Participants mourn the loss of their familiar, comfortable and silent body and struggle to come to terms with a body and a self that no longer feels whole –

'I've never been my whole self yet' (Participant 13 – Interview 1). In addition, they are reminded every day of the things they are no longer able to do, a finding also reported by the 7 women in Ironside et al's (2003) study.

5.5.2.2 Loss of confidence/coherence

For most, alteration in physical appearance and functioning results in a loss of confidence in their ability to function socially or in social roles. One young man was particularly sensitive with regard to his physical appearance, which contributed to his lack of confidence.

I'm not going to join a gym – that confident to join a gym – (self)
conscious wise! (Participant 5 – Interview 2)

His perceived unattractiveness is played out ultimately in an inability to enter into or sustain an intimate relationship. He said of his confidence with girls – 'shot to bits and it's a huge, huge thing' (Participant 5 – Interview 2). Furthermore, the ubiquitous presence of the condition leads to shame and embarrassment that gradually erodes self-esteem and serves as a constant reminder that he is ill.

I was puking the whole way...it was the first time I met her...I was
absolutely mortified (Participant 5 – Interview 2)

This loss of confidence in respect of intimate relationships is a feature of the experiences of the young, unattached men in the study. For some, however, it is the lack of visible manifestation of chronic pancreatitis that causes difficulties. 'I know to look at I look relatively normal. (Participant 4 – Interview 2). In these situations disclosing the nature of their condition is problematic because of social appropriateness.

you know at what point do you go...'hi...by the way before I ask you
do you want a drink there's something I've got to tell you
(Participant 1 – Interview 2)

In addition, they would not burden somebody else with all that living with the condition entails 'I wouldn't inflict it...it would take a very understanding woman...' (Participant 1 – Interview 2). Whether this burden of disclosure is related to a fear of rejection is speculative. However, Ciambrone (2001) found it was a factor in why women with HIV/AIDS experienced loss of intimacy. Nonetheless, implicit in each of these young men's experiences is the notion of a threat to their identity as desirable men worthy of the attention of another person.

Although loss of confidence related to intimate relationships is confined largely to the experiences of young men in the study, it is also a concern for one married woman. Loss of libido was a factor for her because of a loss of confidence in her marriage overall – 'I was so afraid that really our marriage was in trouble because of me' (Participant 7 – Interview 1). For others who were married, their confidence in their relationships was not affected by loss of intimacy.

as regards sex we don't have... because he knows I'm not able...he's very understanding...that's changed but we're still very close
(Participant 6 – Interview 3)

However, an inability to continue in their determined roles within the family and social context impacts on their confidence. Although mediated by life-stage, being able to work, sustaining or contributing to the household or being a good wife/husband/parent are roles that define them. Erosion of these roles through illness results in a loss of confidence, which in turn appears to be a determinant in their loss of coherence – 'I'm too young to be retired, I'm only 54' (Participant 8 – Interview 1).

it would be the best thing for me to do, to get away from them – them being the both of them because I can put somebody that I see as a better mother and wife in my shoes (Participant 7 – Interview 1)

For those who remained in employment or who retained professional and academic aspirations, such losses are perceived as unacceptable...‘I would go mad not having a job...life wouldn’t be worth living’ (Participant 10 – Interview 2), whilst another said of the potential loss of a future is his chosen field:

it’s an amazing gift...if my condition stopped me from doing that, that would obviously be big (Participant 4 – Interview 3)

Loss of coherence for the participants is a sense that all is not as it should be, life progression is no longer predictable and life-plans or goals are disrupted. A diagnosis of chronic pancreatitis is perceived as life-limiting both in terms of personal and professional goals and for some, life purpose is questioned. For most, there is a pervasive sense of uncertainty about the direction in which their lives are going.

I don’t know where it’s going to end really...or when it’s going to end, or if it’s going to end (Participant 6 – Interview 1)

the future...I don’t see a lot of options in the future (Participant 7 – Interview 3)

5.5.2.3 Loss of control

Associated with the sense of uncertainty and unpredictability is a perceived loss of control over various aspects of their lives. There is a loss of control over the illness trajectory due to its uncertain course and prognosis – ‘it’s in the lap of the gods what now happens with it’ (Participant 1 – Interview 1). In addition, participants experience a sense of a body outside their control.

there are these things and they’re happening in your body that you’ve no control over (Participant 3 – Interview 2)

This is often intensified by treatment regimes or medications that exacerbate debilitation. Loss of control of physical self sometimes results in a sense of being defined by the condition – ‘the illness is taking me over’ (Participant 6 –

Interview 2). For others, a sense of being vulnerable generates a feeling of having lost psychological control.

not to feel in control of it...I've always been strong, always had the answers, and now I feel vulnerable (Participant 3 – Interview 2)

One woman attributes her sense of psychological well-being to being in control of events. Unexpected disruptions lead to a sense of being unable to cope.

I am only really happy when things are going along without any bumps in the road (Participant 7 – Interview 3)

There was also a perception that others (mainly healthcare professionals) were in control of their lives and this was frustrating.

the control being in other people's hands and them not handing any of that over to you is just intolerable (Participant 4 – Interview 3)

Loss of healthy self, confidence, control and coherence as described here can be related to the concept of sense of coherence, which is central to Antonovsky's (1987) salutogenic model of health. Sense of coherence is a global personality disposition that expresses the extent to which one has a pervasive, enduring though dynamic, feeling of confidence that one's environment is predictable and that things will work out as well as can be expected. One's sense of coherence develops over time as a result of life experiences and resources and is usually stabilised by young adulthood. It has three components – comprehensibility, manageability, and meaningfulness (Antonovsky, 1987). Comprehensibility, the cognitive component, is the extent to which events are perceived as being ordered, consistent, and structured. Manageability, the behavioural component, is the extent to which a person feels they can cope. Meaningfulness, the motivational component, is how much one feels that life makes sense, and that challenges are worthy of commitment.

These are predicated on general resistance resources (Antonovsky, 1987) such as material (money), knowledge/intelligence, coping strategy, self-esteem, preventative health orientation, social support, commitment and cultural stability (Lindström and Eriksson, 2005; Eriksson and Lindström, 2007). Because of the resources at their disposal persons are provided with sets of meaningful and coherent life experiences that can be used and re-used as necessary (Lindström and Eriksson, 2005).

The findings of studies conducted on sense of coherence, quality of life and life disruptions such as chronic or critical illnesses (Söderberg et al., 1997; Karlsson et al., 2000; Nesbitt and Heidrich, 2000; Dantas et al., 2002; Cohen and Kanter, 2004; Fok et al., 2005; Falk et al., 2007) appear to support the proposition that people with a strong sense of coherence have a perceived higher quality of life than those determined to have a weaker sense of coherence. However, one difficulty with studies of chronic illness (Söderberg et al., 1997; Nesbitt and Heidrich, 2000; Cohen and Kanter, 2004; Falk et al., 2007) is that it is not possible to determine the strength of the person's pre-illness sense of coherence. Thus, whilst it is generally accepted that sense of coherence mediates perception of the illness stressor, the effect of the illness on sense of coherence is unknown.

Nonetheless, fundamental and enduring change in one's life situation can affect one's sense of coherence (Antonovsky, 1987). Therefore, it seems logical to propose that for the participants in this study where altered self-concept and erosion of self-esteem appears to occur, cognitive, behavioural and motivational capacity will be affected, albeit not necessarily in a permanent way.

5.5.3 Feeling down

For these participants, multiple losses generate a range of emotional responses, the most prevalent of which they describe as 'feeling down'. Words that were used synonymously with 'feeling down' included 'depression', 'feeling low' or being 'fed up'. Although the use of the word 'depression' has a psychopathological resonance (Bowman, 2001), it is evident from the participants' discourse that their usage of it is in keeping with the everyday

lay interpretation of the word. This is verified in their general insistence that they are not depressed – ‘I don’t think I am depressed – I get down’ (Participant 7 – Interview 2).

Most participants identify that ‘feeling down’ or ‘feeling low’ is a transient state and fluctuates with the severity of physical symptoms and associated loss of functioning.

at the moment I get very down...I could be on a high and suddenly the pain comes and it’s like ‘oh no, not again’ (Participant 10 – Interview 3)

At these times, they become more conscious of the limitations imposed by the condition – ‘I’m kind of locked in then – I can’t go (out)’ (Participant 8 – Interview 2) and future potential losses or threats are magnified – ‘you get pessimistic because there’s no magic cure on the horizon’ (Participant 1 – Interview 3).

‘Feeling down’ affects mood – ‘feeling low, moody and short-tempered’ (Participant 13 – Diary entry), which in turn affects how the participants behave. This behaviour manifests itself in different ways but most tend to become contemplative and withdrawn. They find it difficult to feel motivated and little interests them – ‘I have no interest in nothing at the minute...I’m just not motivated for it’ (Participant 8 – Interview 2). They are more likely to be ‘grumpy’ or ‘cranky’ particularly in their interactions with family members.

the only thing I really don't like is if my bad mood starts to make me treat someone like herself differently (Participant 4 – Interview 2)

At these times they display a general unwillingness to interact with others and tend to physically and emotionally detach themselves.

even going to work last night I was depressed, fed up, didn’t want to talk to nobody (Participant 12 – Interview 2)

This participant's situation is exacerbated by his declared dependence on alcohol so when he gets depressed/fed up he says - 'all I can think about then is drink' (Participant 12 - Interview 2). This in turn intensifies his negative moods as he wants to drink alcohol but knows that if he does so he is likely to develop pain and vomiting.

An important point here is that most participants consider these feelings as a normal reaction to their situation.

you're not suffering from depression - you're just pissed off about how things are (Participant 5 - Interview 2)

Nonetheless, some specify that their plight is such that, at times, they have wanted to die or wished they could do so - 'this is the first time where I've got to the point I'm saying I want to die' (Participant 3 - Interview 1). However, these comments appear to be related more to their perception of the limit of their tolerance in respect of the condition than a genuine wish for death.

(life) won't be worth living - I couldn't live another five years like that (Participant 5 - Interview 3)

It was evident that they had undertaken some assessment as to whether this meant they were suicidal because each person followed these statements with comments such as,

to do yourself in would be a selfish thing to do (Participant 5 - Interview 3)

it never occurred to me to commit suicide or anything like (Participant 13 - Interview 1).

Because these feelings are considered a justifiable response to their condition, the participants rarely draw healthcare professionals' attention to this aspect of their living with chronic pancreatitis. Only one participant was on anti-

depressant medication and attending a psychiatrist and counsellor at the time of the study. The referral was triggered when he disclosed an accidental overdose with analgesia, which raised medical concern that it was a subconscious attempt to die. Nonetheless, he was adamant that his 'depression' was attributable to his illness and the anti-depressant medication was to facilitate relaxation rather than making him feel better about his situation. He was unwavering in his view that he did not want a false sense of happiness:

'I'm not taking tablets that will do that' I said, because I've nothing to be happy about so what's the point in having a false sense of...things are going right (Participant 5 – Interview 2).

Few comparable studies highlight 'feeling down' or 'feeling low' as themes that feature in living with a chronic illness although Fraser et al (2006) highlighted that some of the participants in their study did allude to such states. However, the finding was not prominent and did not appear in their themes. Nevertheless, in other studies where the focus is participants' perspectives, depression and depressive mood states are identified (Sullivan et al., 2003; Lütze and Archenholtz, 2007). To some extent, these appear comparable with the moods outlined by the participants in this study. However, the terminology differs essentially between the studies and as such presents difficulties with interpreting what is meant by 'depression'.

Nonetheless, there is a generally held view that those with chronic illness are more likely to develop depression (Bottomley, 1998; Beal and Stuifbergen, 2007; Moussavi et al., 2007) and greater depressive symptoms are more common in the presence of a change in functional status and persistent pain (Tsai et al., 2003; Beal and Stuifbergen, 2007). In Moussavi et al's (2007) extensive world health survey (n=245,404), an average of between 9.3% and 23% of participants with one or more physical diseases were diagnosed as having co-existing depression.

However, findings regarding levels of depression and determination of what constitutes clinically significant depression must be interpreted with care. For

example, in Moussavi et al's study (2007), the ICD-10 diagnostic criteria for research for depressive episodes cover a broad range of symptoms that do not distinguish between those that occur because of the physiological impact of the condition, such as fatigue and weight loss in chronic pancreatitis, and their corresponding occurrence as indicators of depression. Furthermore, they exclude adjustment disorders, which because they are associated with the presence of psycho-social stressors may be more appropriate for the assessment of depression in those with chronic illnesses. Bottomley (1998) argues that levels of anxiety and depression can be influenced unduly by the psychometric tool and variations and a lack of standardisation precludes meaningful comparison across studies. Thus, there is an argument that any tool used for assessment of the presence of depression must be well validated and applicable to the population being studied.

Little work has been undertaken on assessing for the presence of depression in people living with chronic pancreatitis. Petrin et al (1995) used the Zung Self-Rating Depression Scale but found no evidence of clinical depression in their cohort of 60 patients with chronic pancreatitis. However, more recent quality of life studies indicate that depression is a feature of the condition (Wehler et al., 2004; Fitzsimmons et al., 2005; Pezzilli and Fantini, 2005). Using the mental component of the SF-36 Wehler et al (2004) determined that clinically significant depression was evident in one in four of their 212 patients.

Although at the time of this study, the participants did not consider they were depressed, they are at increased risk as persistent losses physically and psychologically can progress to a depressive state (Wehler et al., 2004). Yet, routine assessment of their emotional state has not been part of their healthcare to date and if they do not disclose their feelings voluntarily they are not addressed in consultations with healthcare professionals.

5.5.4 Worry

In this study, worry, as an emotional response, is primarily anticipatory, in that the participants are apprehensive about the possibility of the onset of an acute event or the development of noxious stimuli such as pain. Importantly,

this is not a persistent state and is usually preceded by changes in body sensation or body performance.

sort of numb feeling down left side under rib cage and across lower abdomen – bit worrying really (Participant 13 – Diary entry)

This period of worry involves waiting, observing and attempting to determine if their condition will deteriorate. They become what Jerlock et al (2005) describe as body fixated – ‘you’d be kind of waiting, you’d be worrying yourself’ (Participant 8 – Interview 3). During this waiting time, worry about ‘being ill’ superimposes on their worry about bodily sensations and is perceived to aggravate their physical condition – ‘the worry of being ill can often make you feel worse’ (Participant 4 – Interview 1). In a finding similar to that of Dewar and Morse (1995), many of these worries occur at night,

it’s like during the day you’re too busy – it’s only at night time you ever think about it (Participant 14 – Interview 2).

Therefore, for these participants worrying is a process of repeatedly thinking about the potentially negative outcomes of a worsening of vague bodily sensations. Although some recognised the futility of their worrying, they were unable to control these thought processes and for a few it interfered with sleep. One participant reported more severe physical manifestations of his worry.

then you’re worrying about not worrying and then all of a sudden you’re building up all these kind of palpitations and all of a sudden...just water in the mouth...like a nervous kind of sick...anxiety... (Participant 12 – Interview 2)

To some extent, these excerpts demonstrate that sources of worry and subsequent responses vary. What constitutes worry and how it is expressed is influenced by personality traits, coping styles, culture and social environment (Affonso et al., 1999) and the perceived significance of the source of worry. Therefore, its expression can be on a continuum from what might be

considered a normal emotional response based on realistic or natural worries to potentially pathological or incapacitating levels of anxiety (Gliatto, 2000). That the worries and behavioural responses of the participants in this study appear to be realistic in that they are grounded in the existence of chronic pancreatitis does not preclude escalation of anxiety levels in the event of persistent physiological assault and continuous unacceptable changes to their lives.

Yet the meaning of anxiety itself has been the subject of considerable debate, not least of which is whether it is synonymous with stress or a consequence of it (Lazarus and Folkman, 1984). There have been a plethora of studies addressing anxiety in illness but the range and variation of empirically based measurement tools make it difficult to draw conclusions as to what constitutes clinically significant levels of anxiety (Bottomley, 1998; Heikkilä et al., 1998; Taylor-Piliae and Molassiotis, 2001; Ahlberg et al., 2004; McCormick et al., 2006). Nevertheless, what these range of studies indicate is support for Izard's, (1991) contention that anxiety is not a unitary phenomenon but a complex pattern of emotion feelings. He continues that the feeling state common to all anxiety is fear. On this basis, it could be argued that the worries outlined by the participants in this study are essentially inseparable from their fears and are expressed in various behavioural and emotional responses.

Yet worrying is not without its benefits as it can facilitate mobilisation of resources designed to minimise the impact of the potential threat. For example, in this study, the participants reported how their worry about changes in body sensations prompted a period of body monitoring and observing. Their subsequent judgement about the significance of the symptoms was instrumental in how they managed the situation.

5.5.5 Being angry

Several of the participants expressed that they were angry. Anger as a primary emotion has mainly negative connotations and, if directed inwards and combined with other emotions such as those described above by the participants in this study, can lead to depression (Izard, 1991).

For most of the participants in this study, anger is directed outward towards others, their situation and the systems with which they come in contact as a result of living with chronic pancreatitis. In interactions with family or those close to them they are likely to display signs of anger and whilst for the most part this is limited to being irritable, one woman declared:

there is a huge anger in me and I need to deal with it because it can be frightening at times (Participant 7 – Interview 1)

This irritation and anger is often the result of unremitting pain where Izard (1991) declares the anger threshold is lowered. However, anger is rarely enacted and is confined mainly to verbal responses when they feel they have been provoked – ‘she said, ‘that’s what you’re going to end up like’ – I lost the head’ (Participant 5 – Interview 2). The feeling of being judged by others, particularly healthcare professionals is a main source of anger.

I had a good stare to let him know I wasn’t dead...what gave him the right to judge me, ‘cause he did (Participant 2 – Interview 1)

For one man, his original diagnosis of chronic pancreatitis due to hyperlipidaemia altered to ‘alcoholic pancreatitis’ (Participant 14 – Interview 2) in his records when his care transferred from his original medical team. He was unaware of this until his claim for mortgage protection was rejected whereupon he discovered the change. The negative implications of what he describes as an untruth has fuelled his anger significantly. However, controlling such anger and frustration is deemed to be important and often mediates how the participants respond to others.

I was actually going to go out to (hospital name) and confront him with it, then I thought better of it ‘cause I’d only lose the rag with him (Participant 14 – Interview 2)

In Dewar and Morse’s (1995) study of unbearable aspects of illness, participants described incidents that contributed to loss of control. Some of

these related to interpersonal interactions with healthcare professionals where not being believed, lack of explanation about the illness or its treatment, discourteous behaviour by others and lack of recognition were some of the factors that contributed to a build-up of tension and sometimes a loss of control that manifested in verbal and, more rarely, physical aggression. Although the participants in this study did not report any feelings of aggression towards healthcare professionals, they did indicate that at times they felt 'stung' into responding to comments as a defensive gesture.

he actually accused me – in hospital – 'did you have a drink last night?' And I looked at him 'are you for f***ing real?' (Participant 14 – Interview 2).

Anger toward healthcare providers was also a feature of Penckofer et al's (2007) study of women living with diabetes and Rätty and Gustafsson's (2006) exploration of healthcare encounters of 10 people with epilepsy. In the former, negative feedback rather than encouragement and the perception that they were somehow to blame for their condition contributed towards the women's anger. This resonates with the participants in this study, many of whom experience varying levels of negative stereotyping and labelling because of the relationship between alcohol and chronic pancreatitis – 'it does irritate me that image of CP as self-inflicted' (Participant 1 – Interview 1). This is epitomised by one man who felt the label of alcoholic, prior to diagnosis, precluded adequate investigation of his symptoms and could have caused his death. Two years after the diagnosis he continues to be angry about how he feels he has been treated.

I was angry that day, not enough investigations – only what he was saying to me all the time – it's drinking, drinking...straight away, he never looked (Participant 2 – Interview 2)

Being prevented from achieving goals is a source of anger and whoever or whatever is seen as the restraining force is blamed (Izard, 1991; Bowman et al., 2006). For some of the participants, being restrained from functioning as they had in the past is a source of anger directed towards the illness itself – 'I

just want to get on with a normal life' (Participant 6 – Interview 1) that is intensified by having to rely on medication. This was also a finding in Sullivan et al's (2003) study of 120 women with either cancer, diabetes, rheumatoid diseases or multiple sclerosis, where the illness was hated because they could no longer function as they used to.

Participants felt they were restrained also by the infrastructure and processes within the healthcare system. Treatment regimes, interacting with health and social care personnel, dissatisfaction with care, waiting for investigation and treatment all contributed to their feelings of anger and frustration. For one man, the wait for investigations that might confirm his diagnosis was a source of anger:

I could almost get quite angry about it because it's like a lack of effort...or there isn't the infrastructure – for me it means countless months of pain (Participant 4 – Interview 3)

This anger was echoed by several of the participants who feel their illness trajectory has been affected negatively by a considerable time lag between initial symptoms and diagnosis as they continued with a life style they now know was detrimental.

Similar to Fitzsimons et al (2000), others feel that lack of information or the opportunity to ask questions is a source of frustration and anger – 'that's so f***ing annoying and irritating...by the time you go to ask a question...'next' (Participant 12 – Interview 2).

Particular to this study is that six of the participants live a considerable travelling distance from the hospital where their care is based. Because of this they become angry when appointments are cancelled without notification or if they perceive they have made the journey for a brief and unsatisfactory consultation – 'appointment at 11 o'clock, out by five past, next train wasn't until five past three' (Participant 5 – Interview 2). Distance also becomes an issue when acute episodes necessitate hospitalisation. At times, the onset of symptoms demands immediate help with the result that participants are

admitted to their local hospital. They become angry and frustrated when they perceive the 'expertise' to treat them is not available or that the treatment is 'incorrect' or is at odds with what is being done in their main hospital of care.

cortical stimulator – they were trying to tell me they never did that in (hospital name) – they were badmouthing them (Participant 5 – Interview 2)

These feelings become exaggerated and intermingled with fear when trying to impress the need for transfer to their main hospital. At times, the participants perceive resistance from healthcare professionals, which is accompanied by a protracted process of waiting either for agreement on the need for transfer or for an available bed.

Some chronic illness studies of those who live in rural settings, support this finding that travelling long distances is frustrating and debilitating (Sullivan et al., 2003), while waiting was a source of frustration and anger in studies of those awaiting surgery (Fitzsimons et al., 2000; Hagren et al., 2001; McCormick et al., 2006).

In addition, some participants become angry with the social welfare system. They associate this with the need to verify chronic pancreatitis as a permanent and disabling condition. On first application for disability allowance, several were rejected and had to appeal the decision.

I had to battle to explain to them 'look CP is an ongoing condition, it doesn't go away, it doesn't get better – it's progressive...it is a genuine disability...I do need help' and that was accepted eventually (Participant 1 – Interview 1)

Underlying several of the participants' anger is a sense of injustice at being burdened with chronic pancreatitis. Even when they believe a clear causal factor, such as alcohol was implicated in the development of the condition, they ask 'why me?' This sentiment is often a reflection of how they perceive

the unfairness in relation to others whose behaviour is more risky yet they are not afflicted.

I see people walking about that really take their life for granted – I look at people that are constantly smoking or constantly drinking that have a 100% bill of health and it's very hard not to become angry (Participant 4 – Interview 3)

One participant verbalised her sense of unfairness and anger by referring to others who do not bear their illnesses or conditions with fortitude or who complain unnecessarily.

and you feel like telling them to shut up...I have chronic pancreatitis...why doesn't anybody listen to me? (Participant 6 – Interview 1)

The sense of being unfairly burdened as a source of anger is echoed in Lütze and Archenholtz's (2007) study of the impact of arthritis on daily life. In addition, the participants in their study became angry when they were unable to perform their activities but also when pain and fatigue reminded them of their helplessness.

The causes of anger as outlined here are in accordance with those outlined by Izard (1991). Yet anger, like worry and fear, can motivate resources for self-defence and in the case of psychological defence can lead to appropriate assertiveness. There is some evidence in the participants' accounts that their anger is a motivating factor in choosing courses of action in the management of their condition, an aspect that is discussed in the following chapter.

5.5.6 Summary

Enduring psychological disruption has been described here as an altered self in illness manifested in a sense of 'disturbed normal' and articulated as moods and feelings that incorporate 'being afraid', 'loss', 'feeling down', 'worry' and 'being angry'. The process of identifying and extrapolating these discrete emotional and psychological responses as part of the analysis of data was

difficult because among the study participants they rarely occur in isolation. Therefore, their linear presentation for the purposes of description and discussion does not adequately reflect their interrelationship. Furthermore, these emotional and psychological responses are mediated by individual personality traits and the social and cultural milieu in which the participants live. Thus, the interplay between the occurrence of discrete emotions, moods and feelings and the level of intensity at which they occur can only be determined ultimately by the individual experiencing it.

5.6 Interpretation

For the participants in this study, the three unifying categories of enduring physiological disruption, enduring social disruption and enduring psychological disruption describe the construct of enduring (permanent and perpetual) disruption. Furthermore, it has been demonstrated how the unifying categories are interrelated and have a symmetrical relationship. Moreover, the manner in which the themes and sub-themes are interwoven reflects the various dimensions of enduring disruption arising from living with chronic pancreatitis. Although individual variations occur, this interplay of themes and sub-themes within each category illustrates the complex and multidimensional nature of the impact of the condition and signifies the disparity between the person one was or wished to be and the person one now is with chronic pancreatitis.

Critical analysis of and reflection on the interrelationship between the unifying categories and the configuration of themes and sub-themes therein leads to the proposition that for those living with chronic pancreatitis enduring (perpetual and permanent) disruption represents 'suffering'. Although the concept and its attributes have been variously represented in the literature, the meaning drawn upon herein is the contemporary view of it as occurring in the 'whole person as a state of distress induced by the threat of loss of intactness or disintegration from whatever cause' (Arman and Rehnsfeldt, 2003:511).

Being disrupted from one's wholeness is common to all suffering (Arman and Rehnsfeldt, 2003) and it is conceived as being evil and undesirable (Lindholm and Eriksson, 1993; Lindholm et al., 2002b). Despite its malevolence, the literature appears to be in agreement that suffering is a naturally occurring phenomenon that is part of life (Lindholm and Eriksson, 1993; Hagren et al., 2001; Arman and Rehnsfeldt, 2003). It involves the assignment of an intensely negative meaning to an event or perceived threat (Kahn and Steeves, 1986; Rodgers and Cowles, 1997). However, it is also a concept that can only be characterised, not measured, as it is subjective, individualised and multidimensional (physical, psychological and social) (Rodgers and Cowles, 1997; Chapman and Gavrin, 1999; Lindholm et al., 2002b).

Nonetheless, three forms of suffering have been identified in the literature; suffering caused by illness and treatment, suffering caused by care and suffering that relates to existence (Lindholm and Eriksson, 1993).

In chronic pancreatitis, as explicated by this study, the three forms of suffering are clearly seen (Figure 5.5). The physiological assault associated with unpredictable daily and salient disruptions and the attendant treatment regimes represents suffering related to illness and treatment. At times, this suffering is amplified by that which arises in the context of healthcare and through relationships with healthcare professionals (that is, suffering caused by care). Interactional and interpersonal situations in which the participants feel disempowered, uncared for or experience loss of dignity represent this type of suffering (Arman et al., 2004).

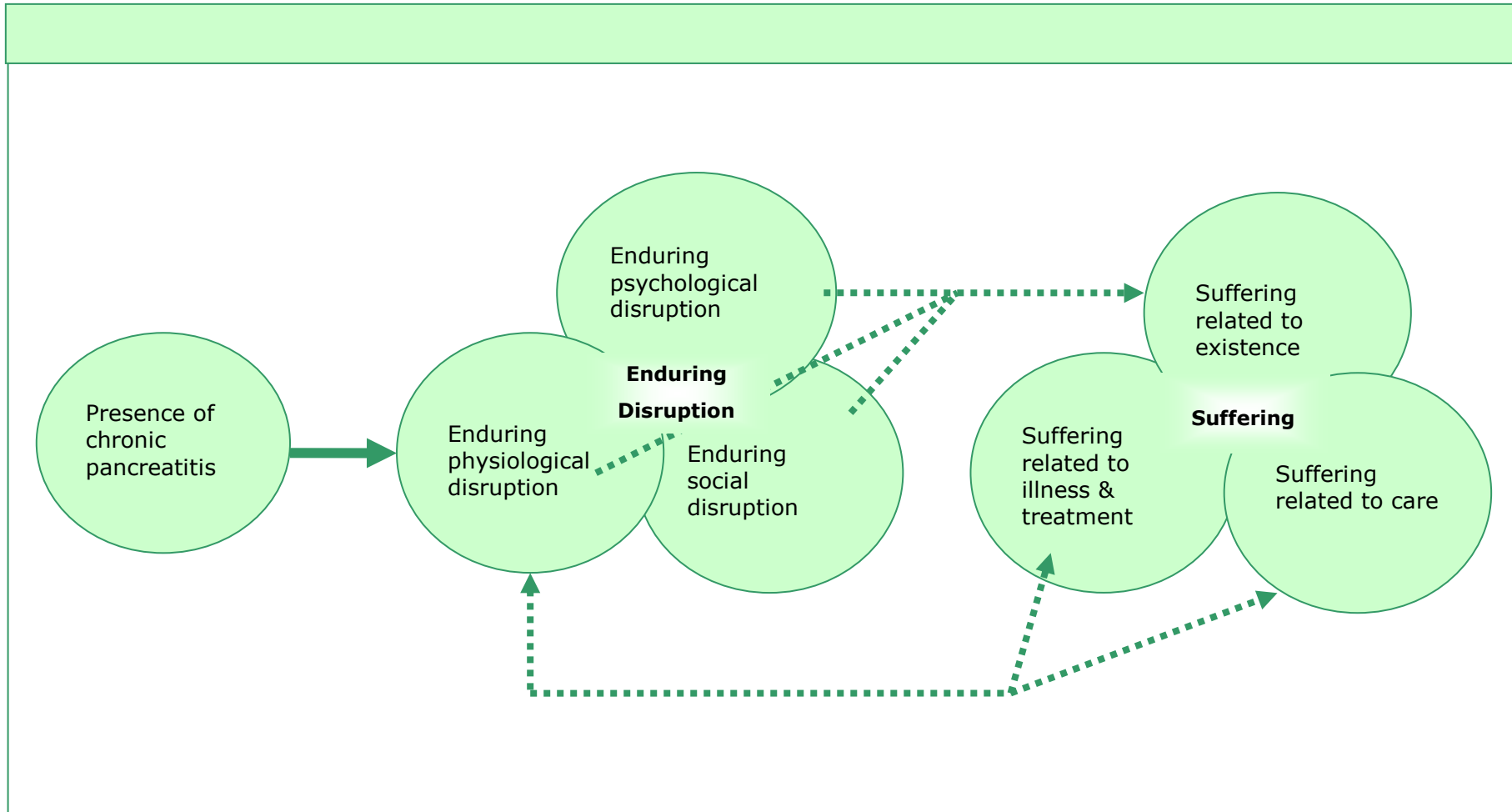
Furthermore, enduring physiological disruption and all it entails constitutes a threat to the integrity of the self, which is compounded by compromised physical and social functioning. Moreover, the unpredictable nature of the symptoms and the uncertain yet progressive illness trajectory provoke psychological and emotional responses to threat indicative of psychological distress (Massé, 2000; Andenæs et al., 2004; Ridner, 2004). Each person judges the meaning of their living with chronic pancreatitis within the context of their own lives and living, but for most it is evaluated negatively. Many feel they are no longer able to control their present and the future is unpredictable. Uncertainty and vulnerability that materialise as a consequence of tangible physical and social losses and psychological symbolic losses contribute to psychological distress and generate suffering related to existence.

Finally, it is conceived that suffering as it is characterised in chronic pancreatitis is endless and likely to never be alleviated fully because of the nature of the condition and the potential for new problems associated with disease progression and further disruption in physical, social and psychological functioning. Furthermore, it is not a steady state and oscillates on a continuum from tolerable to intolerable. Thus, the three forms of suffering identified above may not occur simultaneously or exist in isolation or

with the same degree of intensity. It is their particular configuration in the context of each individual's unique situation that ultimately determines perception of their tolerability.

Enduring disruption as it is described in this chapter, where 'enduring' is used as an adjective, could be said to constitute the 'what' of suffering (Arman and Rehnsfeldt, 2003). The following chapter addresses how the participants deal with their suffering. This has been identified as the verb 'to endure' meaning 'to cope with' and/or 'to tolerate' and for the participants is about how they are learning to live with chronic pancreatitis. It essentially addresses a process of how they confront their suffering both in terms of their altered selves and altered lives.

Figure 5.5 Suffering in chronic pancreatitis



CHAPTER 6 – PRESENTATION AND DISCUSSION OF FINDINGS

ENDURING DISRUPTION – ‘TO COPE WITH’ AND/OR ‘TO TOLERATE’

6.1 Introduction

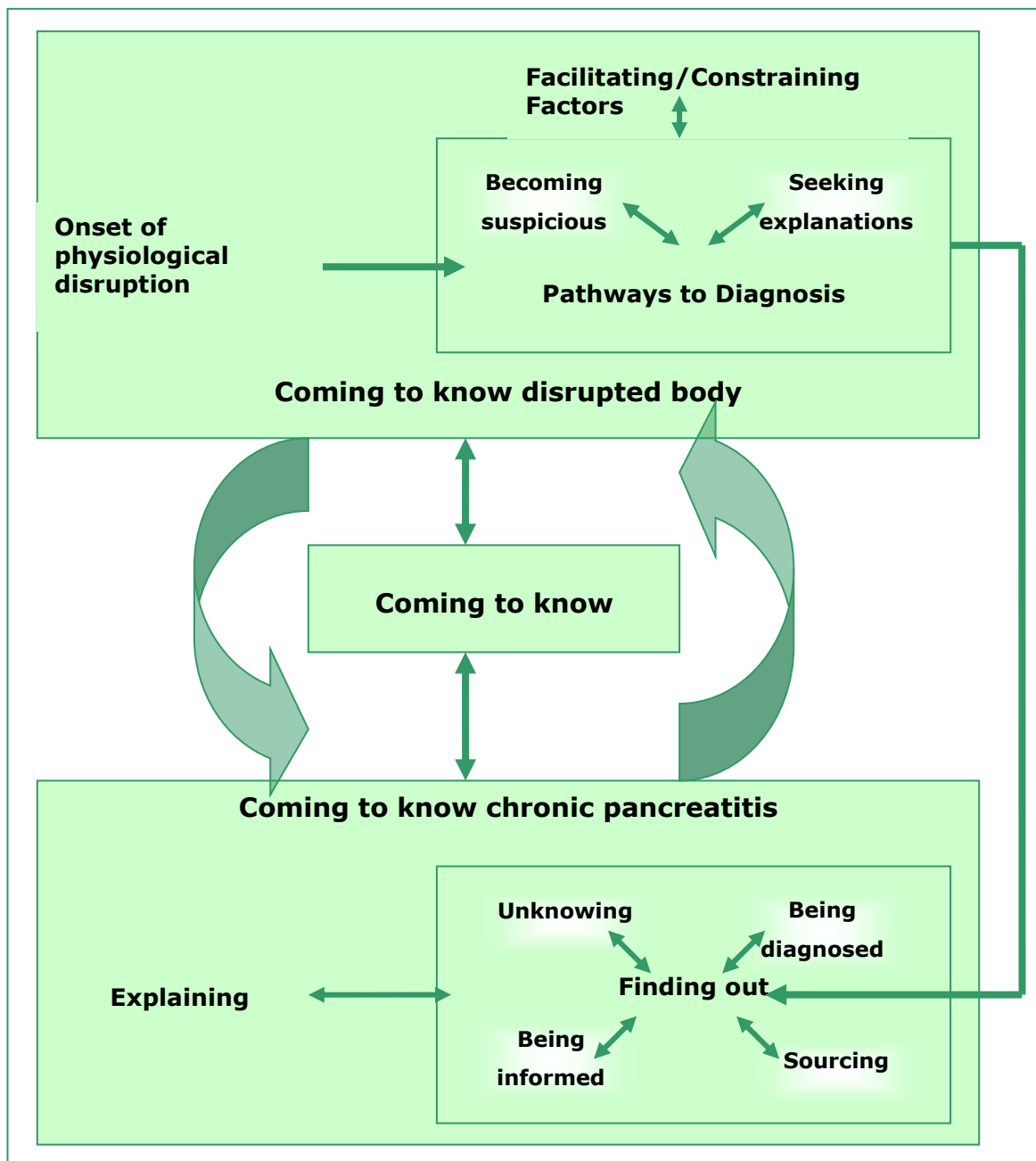
This chapter focuses on explicating the second meaning of enduring within the context of this study. ‘Enduring’, as a verb means ‘to cope with’ and/or ‘to tolerate’ and in respect of its semantics is always in the context of withstanding adversity or difficulty (Hawker, 2006). Therefore, for the participants and their families it is about how they cope with and are learning to live with chronic pancreatitis. Coping concerns the processes by which the participants and their families continually appraise and reappraise the demands placed on them and how they think or act in those situations. An important point is that coping or tolerating in the sense in which it emerged occurred within the overall health/illness transition from ‘well’ person to a person who lives with chronic pancreatitis. This transition is explicated as comprising ‘coming to know’ and ‘adjusting/managing’. The central thesis is that coping mediates the conditions in the transition experience. Therefore, progression is not a strictly linear process, but can fluctuate depending on changes in the nature and severity of the symptoms, the perceived significance of the social impact of the condition and the emotional and psychological responses to all that the illness entails.

6.2 Coming to know

For the participants in this study ‘coming to know’ marked the beginning of living with chronic pancreatitis. It essentially addresses the process by which the participants came to know physiological disruption and the condition of chronic pancreatitis. ‘Coming to know disrupted body’ and ‘coming to know chronic pancreatitis’ constitute the two major themes. Coming to know disrupted body addresses the stages of ‘onset of physiological disruption’ and ‘pathways to diagnosis’ whilst coming to know chronic pancreatitis incorporates ‘finding out’ and ‘explaining’ (Figure 6.1). For the purposes of this discussion, coming to know disrupted body focuses on the initial phase of physiological disruption to the point of diagnosis. This is because the participants identified that the handling of events in this pre-diagnostic phase

determined, to some extent, progression to diagnosis. Despite the physiological disruption experienced in the pre-diagnostic phase, participants identified 'being diagnosed' as representing the beginning of 'finding out' and coming to know chronic pancreatitis. Finding out also encompasses sources of information and means by which the participants learned about the condition. This includes 'being informed', 'sourcing' and 'unknowing'. 'Explaining' includes the participants' beliefs and understanding about the condition and why they developed it.

Figure 6.1: Coming to know



6.2.1 Coming to know disrupted body

6.2.1.1 Onset of physiological disruption

All participants determined that coming to know disrupted body began with the onset of physiological disruption and essentially constituted the critical point that marked the beginning of the transition from health to illness. The onset of physiological disruption was significant for a number of reasons. Primarily, although the participants identified the symptoms as noxious and thereby harmful and/or threatening many did not seek help until the symptoms were so severe as to render them incapacitated: 'it started getting worse and worse ...I said I'd carry on till dinner time' (Participant 8 – Interview 1).

Initially, several of the participants identified individual and situational factors that accounted for the onset of symptoms and mediated their help-seeking behaviour. As outlined in the previous chapter, these included pre-existing, temporary or alcohol-induced conditions.

I didn't feel well, which I was putting down to the hiatus hernia
(Participant 6 – Interview 1)

I was drinking an awful lot at the time (Participant 8 – Interview 1)

In constructing these symptom representations, participants were able to draw parallels with previous experience of gastrointestinal disturbances and by inference believed the symptoms would resolve. However, with non-resolution, worsening or increasing symptom severity, they deemed the assault to be beyond their coping resources and healthcare professionals were consulted.

I was into the fourth day since I drank and then I started vomiting
blood – I thought 'holy s***' (Participant 3 – Interview 1)

For those who could not account for the onset of the symptoms, assessment of the perceived immediate harm combined with the severity of the symptoms appeared to provoke early help-seeking behaviour. These participants could

not construct a symptom representation from any previous experience and therefore the threat seemed to be greater.

it was a mystery to me...I was so bad that I had to get a GP, I was so bad I couldn't even get out to walk, to get to the hospital
(Participant 1 – Interview 1)

An important point is that regardless of factors that mediated their help-seeking behaviour, at this time none of the participants considered the threat to be significant in the long-term. There seems to be two main reasons for this. Those who had constructed symptom representations had these confirmed in consultations with healthcare professionals, whilst those who had no previous representation were assigned diagnoses that were known to them within the general societal knowledge of illness, such as 'ulcers'. Secondly, their personal illness experience and general knowledge regarding the possible causes of gastrointestinal disturbance did not include pancreatitis in any form simply because they did not know about it: 'I'd never heard of pancreatitis' (Participant 6 – Interview 1).

These early experiences demonstrate the complex relationship between appraisal and coping where the seemingly continual movement back and forth made it difficult to distinguish between them for the purpose of analysis and interpretation. Nevertheless, Lazarus and Folkman's (1984) model of stress, appraisal and coping offers a frame of reference for understanding the participants' early responses. That the initial onset of physiological disruption was appraised as immediately threatening or harmful is a logical assumption given that stress appraisals incorporate any encounter that causes damage (actual or potential) to the person (Lazarus and Folkman, 1984). However, that the participants did not initially assess the assault as significant for their long-term well-being represents the influence of personal and situational factors on the processes of appraisal and coping.

In a framework for research on coping, health and illness behaviour and outcome Shaw (1999) proposes that among other factors, illness representation and previous experience mediate perception and interpretation of symptoms. For the participants in this study, it may be that locating the

threat within their realm of experience and knowledge and focusing on an illness representation that incorporated 'cure' made it understandable and explainable, thereby regulating the potential emotional distress associated with the symptoms. This is an example of what Lazarus and Folkman (1984) define as cognitive appraisal/reappraisal of the emotion-focussed type where, although the objective situation remains unchanged, its meaning is altered in order to manage the encounter

Nonetheless, it is evident that most of the participants did not rely solely on emotion-focussed coping. By deeming the severity of the symptoms to be beyond their capacity to deal with them, all sought professional help. In Lazarus and Folkman's (1984) terms this constitutes problem-focussed coping where efforts and actions are directed at managing the situation. Since this has not been studied previously in chronic pancreatitis the findings cannot be interpreted within the context of the present literature. However, Morse and O'Brien (1995) and Griffiths and Jordan (1998) both found that at the time of the original injury their participants demonstrated high levels of cognitive functioning in the face of overwhelming and immediate threat. Thus the findings support the contention that both types of coping occur simultaneously (Lazarus and Folkman, 1984).

At the first point of contact with health care professionals, none of the participants were diagnosed with chronic pancreatitis, which meant that although the health/illness transition may have begun they were not aware of it. This supports Meleis et al's (2000) assertion that although awareness is an important property of transition experiences, lack of awareness does not preclude its onset. Indeed, it is proposed that it would have been difficult for the participants in this study to be aware of a health/illness transition given the circumstances of the onset of symptoms. It was only with continued disruption and non-resolution of symptoms that their awareness of the changes that were occurring was triggered.

6.2.1.2 Pathways to diagnosis

The onset of physiological disruption relates to the time span between the development of symptoms and seeking professional help while pathways to

diagnosis is about the segment of time between initial presentation to a healthcare professional and confirmation of the existence of chronic pancreatitis. This varied significantly across the participants and ranged from 2 weeks to 18 months. In their interviews, participants spent a considerable amount of time talking about this phase of their illness, particularly those who perceived they had experienced significant harm during this period. Analysis of each person's pathway to diagnosis did not reveal any patterns that could be described as representative. The only common feature was that symptoms persisted either episodically or continually. Therefore, symptom experience remained the principal triggering factor for mobilisation of coping resources.

Factors related to symptom experience and the initial diagnosis had implications for the participants' cognitive reappraisal of the situation. With the exception of the woman diagnosed with cancer, for the remaining participants, the initial diagnosis had the temporary effect of reducing the sense of threat or harm. This was largely reinforced in their communications with healthcare professionals where information and advice regarding resumption of normal living or making life-style modifications was interpreted as being key to symptom resolution. For example, three of the four participants diagnosed with acute pancreatitis and the four with alcohol induced stomach or liver dysfunction diagnoses were informed of the importance of abstention from alcohol.

he (doctor) told me I had an inflamed stomach – gave me tablets, told me not to drink for a while – so I done that for two months (Participant 2 – Interview 1).

However, one young man diagnosed with acute pancreatitis reported that he received advice that could be implicated in the subsequent development of chronic pancreatitis.

I said, 'how does this affect my life?' I thought it was a once off thing – get back to normal. He said, 'well drink in moderation...it shouldn't affect your life at all'. Just have a few on the weekend and you should be fine. Just don't go out and get absolutely hammered for two days or something (Participant 5 – Interview 2)

Becoming suspicious

These points are worthy of elucidation because subsequent recurrence or non-resolution of symptoms were appraised in the context of whether the advice from healthcare professionals had been followed. For those who did not make the recommended life-style changes, that symptoms recurred was not altogether surprising to them. This applied primarily to two participants with acute pancreatitis and three with alcohol induced or liver conditions. To a certain degree, these participants' pathway to diagnosis was more passive and did not require active pursuit of explanations. Whilst their symptoms resolved at the outset, they recurred within a short time frame and all subsequently required emergency hospitalisation and/or intensive care treatment. Given their symptom pattern and history, these participants tended to be diagnosed in a shorter time span.

a couple of weeks after I got another belt...I was drinking away... second time he sent me in (hospital) and he discovered my amylase...they were reading 800...very high and they decided it was pancreatitis (Participant 8 – Interview 1)

Those who had instigated the changes or resumed normal living began to suspect that the initial diagnosis did not account for their symptom experience.

I pretty much thought that if I never drank again then I'd never feel ill again...when it came around acutely the second time... (Participant 4 – Interview 1)

Two other participants were hospitalised twice during this period, which increased their suspicions further but acute or chronic pancreatitis was not detected in either case.

Another began to believe he had cancer since his disrupted body, in his view and corroborated by family and friends, showed known warning signs such as fatigue and dramatic weight loss.

I think cancer...it did rear its ugly head. And I did think with the weight loss because from that Christmas onwards the weight was literally falling off him (Family member – Wife).

In these instances, the more severe the symptoms became and the longer they persisted or the more frequently they recurred the more they were perceived as harmful or threatening. This correlates with Lazarus and Folkman's (1984) assertion that the duration of a stressor has a psychological and physical impact on the person. Participants in this study began to experience emotional responses such as fear, worry, frustration and anger.

there were a couple of points where I was very close to either ringing an ambulance myself or trying to get my flatmates up because I was very scared...there was only really three points where I got really, really scared because it felt like something was going to pop (Participant 4 – Interview 1)

Seeking explanations

Despite being distressed, the participants continued to use problem-focussed coping strategies by actively seeking explanations for the symptoms through consultations with their general practitioner or hospital specialists, requesting referrals to other hospitals, seeking second opinions, enduring various investigative procedures and/or seeking information through contacts, books or the internet. One man gleaned sufficient information to suggest to his hospital consultant that he 'specifically look for chronic pancreatitis' (Participant 1 – Interview 1).

Similar problem-focussed strategies were found in studies of the pre-diagnostic experiences of people subsequently diagnosed with multiple sclerosis (Koopman and Schweitzer, 1999; Barker-Collo et al., 2006), diabetes (Peel et al., 2004) and cystic fibrosis (Widerman, 2004). As in the current study, diagnosis or explanation was actively pursued when the pattern of symptoms and degree of suspicion of a serious illness reached a self-defined threshold. However, all but one of the participants in this study and the majority of those in the cited studies did not suspect their 'true' diagnosis. This seems to be related to previous knowledge and experience of the

condition. For example, some participants in the diabetes (Peel et al., 2004) and cystic fibrosis (Wideman, 2004) studies correctly deduced their condition, either because they had read of the condition or knew others who had it.

6.2.1.3 Facilitating/constraining factors

Although symptom pattern and its interpretation accounted, in part, for the time span between initial and definitive diagnosis, there were additional factors that mediated the participants' appraisal and coping and, by association, influenced the pathway to diagnosis.

Constraining factors

Several of the participants voiced personal beliefs and values about illness and illness behaviour that influenced their help seeking. Primarily, this seemed to be based on their culturally bound conception of what it means to be 'sick'. For most, this meant ascertaining whether the symptoms were sufficiently significant to warrant help seeking. Therefore, what might be construed as a 'delay' in accessing healthcare was, for these participants, a period of verification and monitoring. In this way, when they did seek help they felt justified in doing so.

the main reason I didn't go the first and the second time...I wasn't kind of doubled up...I was very embarrassed they'd say 'there's nothing that much wrong with you (Participant 4 – Interview 1)

Underpinning this participant's behaviour then is a belief that in order to be judged as legitimately 'sick' objective evidence must be available to corroborate his experiences.

it was always important for me to really be feeling ill whenever you're in hospital or whenever you're seeing a doctor... my Mum and Dad said 'don't ever say that you're ill because of stress' because doctors...it's always the last thing they want to hear (Participant 4 – Interview 1)

Participants spoke consistently of having to 'convince' the doctor and their gatekeepers such as nurses and medical receptionists that their symptoms were worthy of investigation.

you go to casualty, you've got this triage battle...having to fight your case like a barrister for admittance into the hospital
(Participant 1 – Interview 1)

you get onto a receptionist first for the fifty questions, she puts you onto a nurse – the same 50 questions and a couple of extra ones – you get onto a doctor then (Participant 8 – Interview 1)

This view reflects the participants' conception of their role in the medical encounter but is also an indication of the perceived authority of the doctor, who has the power to determine the pathway to diagnosis and treatment.

what he said to me was '(hospital name) are sending me notes and saying you're responding to treatment, you're getting better.' And I said 'he's not' (Family member – Wife)

This account mirrors the general perception among the participants of the legitimacy of doctors as an 'expert' and an associated reluctance and, to some degree, inability to question their authority. Seeking explanations was fraught with frustrations associated with 'not being believed' and having experiences discounted because of the absence of clinical markers other than their own self-reports.

in fact the specialist that I saw was convinced because of how ill I was, that I must still be drinking (Participant 4 – Interview 1)

Challenging relationships with doctors and powerlessness were also features of the participants' experiences in Koopman and Schweitzer's (1999) and Kralik et al's (2001) studies particularly when they were actively seeking explanations for their symptoms. Kralik et al (2001) claim this reflects the powerful and dominant voice of the doctor in medical encounters. This view is

corroborated by Rees et al (2007) who found that doctors remain at the centre of medical practice.

The findings offer some support for the contention that the characteristics of a disease impact on the pre-diagnosis experience (Widerman, 2004; Tod et al., 2008). As in chronic pancreatitis, these studies reported that where clinical features were symptomatic of other common conditions, diagnosis could be delayed. As stated previously, early chronic pancreatitis is particularly difficult to diagnose (Tinto et al., 2002) and, given its relatively uncommon incidence, may not be an initial consideration when a patient presents with abdominal pain. This may be even more significant if the patient is atypical or if some related morbidity obscures the assessment. As Adamson (1997) argues, when a clinical picture is unclear, clinicians tend to resolve diagnosis on the basis of probabilistic logic. Therefore, although the physiological assault associated with the acute onset of chronic pancreatitis could not be ignored, it was the manner in which healthcare professionals interpreted them that seemed to be the critical defining factor for the participants' subsequent experiences.

Over-arching these experiences were what the participants recounted as frustrations within the healthcare system. These were many and varied and included inaccessible medical help out of hours, prolonged waiting in accident and emergency, extended waiting for investigations and results, misplaced results, poor communication and the perceived limitations with access to specialists associated with being a 'public' patient.

I had waited in (other hospital) for about 12 or 14 hours and I gave up at that point and then just decided to go to (treating hospital)
(Participant 1 – Interview 1)

I had an interview at Prof's clinic...end of February and the scans were booked for June and August...so it's a long wait (Participant 4 – Interview 1)

I phoned (hospital name) because I had an amylase of over a 1,000 and no one knows where it (the blood result) is now (Participant 4 – Interview 2)

I had to drive up to (place name) because at the weekends there's no doctors on here, there's (out of hours service) they call it... I would never have seen (consultant's name) if I wasn't insured (Participant 8 – Interview 1)

Although some issues may be peculiar to the Irish health care system, there is considerable evidence in the international literature that 'waiting' is a feature of all stages of the pre-diagnostic phase from recognition of symptoms to investigation and finally to treatment (Fogarty and Cronin, 2008).

Facilitating factors

In contrast, participants also reported factors that ultimately facilitated diagnosis. Interventions and support by family members were seen as facilitative as were what were described as serendipitous or fortuitous events or meetings. For example, one woman initially diagnosed with cancer spoke of a series of chance events that resulted in referral to her treating consultant, a fact she believes saved her life.

so they decided...it was like playing cards, we'll send a letter to both (consultants) and whoever answers us with a positive first we'll go with them. And, God bless him, (consultant's name) answered straight away (Participant 9 – Interview 1)

For this woman being diagnosed with chronic pancreatitis was infinitely better than having terminal pancreatic cancer and she believes it was the diagnostic skill of the consultant that enabled the discrimination to be made.

Similarly, other participants reported how they 'heard' of their treating consultant through 'lay' and 'professional' sources and were able to seek referral through the general practitioner or privately.

two people gave me (consultant's name) name – one was my brother who heard it through a friend and then a doctor that I'd come across on my travels...she mentioned it and that's how I ended up giving him a ring (Participant 7 – Interview 1)

In this study, family members were an important source of support for the participants in the pre-diagnostic phase. This included emotional support but also practical and intervention support as the situation demanded. On a practical level, family members offered advice, accompanied participants to medical consultations and in some circumstances became their advocate when communicating with healthcare professionals.

my Mum said 'lay it on a bit thick' (Participant 4 – Interview 2)

the first time I went to the hospital with him...I literally had to sit on him in the A&E...he was going to get up and walk out a few times (Family member – Wife)

no matter what I said about he doesn't drink...I always thought they didn't believe me. So then I really wanted him out of (hospital name) because I felt they weren't doing him any good (Family member – Wife)

In other circumstances, family members 'intervened' and took control, with or without the participants' consent, if they felt it was in their best interests or if they perceived the participants were unable to act for themselves.

I had decided then that... I couldn't tell him because I didn't know how he would react. I went down to our GP, and I said to him 'he's really not well' (Family member – Wife)

Of the studies that have examined aspects of this phase of illness, only Fridfinnsdottir (1997) addresses social support directly and classifies it as emotional, tangible and informational. Her findings that emotional and tangible support is provided primarily by the family are congruent with those

of this study. Much of the work of the family members was geared towards finding doctors who would 'listen' and act on their concerns. Taking control and actively seeking doctors who would provide answers was a problem-focussed strategy in the face of frustration and, to some extent, the perceived helplessness of their situation. Ultimately, their actions were significant in facilitating diagnosis for these participants but their experiences also affected how they viewed the care they received. As in Kralik et al's (2001) secondary analysis from three qualitative studies of women with chronic illnesses (n=93), interactions with healthcare professionals that were unsupportive left a lasting impression.

For the participants in this study, the proffered rationale for their reactions and behaviours during this phase of their illness experience are examples of what Lazarus and Folkman (1984) describe as person and environmental factors that can influence appraisal and coping, positively or negatively. Person factors such as their beliefs and values about healthcare appear to have had an impact on the participants' help-seeking behaviour and their interactions with healthcare professionals while environmental factors were associated with constraints within the system.

Poole (1997) suggests that the pre-diagnostic/diagnostic phase is conceptually different from other stages in the illness process since it forms the interface between the suspicion of an illness and medical confirmation of health/illness status. As a discrete stage in the illness trajectory, it has been described as the most stressful (Fridfinnsdottir, 1997; Poole, 1997; Poole and Lyne, 2000; Lebel et al., 2003) because the extent of the threat to well-being is as yet unknown and undetermined.

6.2.2 Coming to know chronic pancreatitis

Coming to know chronic pancreatitis is concerned with the processes of being diagnosed and how the participants learned about the condition. It addresses information provision and sourcing and outlines anomalies and gaps in their knowing as a result of perceived conflicting information and highlights relevant aspects of their unknowing. These factors had some bearing on subsequent actions for coping with chronic pancreatitis.

6.2.2.1 'Finding out'

Being diagnosed

Being diagnosed was the first stage of finding out and marked the beginning of coming to know chronic pancreatitis. All participants clearly recalled the context and their feelings when they were informed of the diagnosis. Although their reactions varied, the overwhelming initial response was one of puzzlement associated with their 'unknowing'.

I actually went 'pancrea what - what's that? (Participant 14 - Interview 1).

With the exception of two participants who had some knowledge of the condition, the remainder had never heard of it. One woman, however, describes how she became 'hysterical' on hearing the diagnosis.

I got a terrible fright when he told me what it was...terminal and chronic go together when you've never been ill...I was in such a state...I was hysterical (Participant 7 - Interview 1)

Others reported feeling an initial sense of relief, which was due mainly to the length of time to diagnosis and that it was not, in their view, a more sinister outcome. Furthermore, it vindicated their concerns and suspicions about the initial diagnosis and the presence of an illness.

I suppose that was a relief when I did go into the A&E and they thought most likely it was chronic pancreatitis because I'd had it since December...so then at least I knew (Participant 4 - Interview 1)

However, one of the men who knew about chronic pancreatitis describes his reaction as 'shock' because he knew of the implications - 'the fact that it's kind of untreatable and it's progressive (Participant 1 - Interview 1). Another recalls how he immediately realised the link with alcohol and potential death.

an ex brother-in-law of mine actually died from it...he wouldn't stop drinking and it killed him for a finish (Participant 8 – Interview 1)

The ability to recall vividly the moment when the diagnosis was confirmed is congruent with the findings of several studies (Koopman and Schweitzer, 1999; Dewar and Lee, 2000; Asbring, 2001; Kralik et al., 2001; Kralik, 2002; Landmark and Wahl, 2002; Widerman, 2004) and is indicative of the significance of the event. However, the emotional reactions of the participants in this study appeared to be more muted than those in the studies cited above, where traumatic reactions such as shock, stress, anger and fear were common. It is likely that this is because even at the point of diagnosis, chronic pancreatitis had little meaning and its ultimate significance for their altered lives was only determined retrospectively and from their position of 'knowing' the condition.

Being informed

The sub-theme of being informed describes being provided with details about chronic pancreatitis by healthcare professionals rather than the self-directed seeking of information from other sources. The provision of information was largely incremental and seemed to depend on the participants' illness experiences following diagnosis. Information was provided mainly by hospital-based doctors with supplementary advice on management of the condition being provided by dieticians, and in a few cases, by a clinical nurse specialist.

At diagnosis, the participants were given causal explanations for the development of chronic pancreatitis but, as typified by one participant 'they never really explained too much about it' (Participant 10 – Interview 1). With the exception of two women and one man who had non-alcohol related diagnoses, all were informed that alcohol consumption was implicated. This was particularly frustrating for one participant who did not consume alcohol and for whom this explanation was inadequate. He was diagnosed subsequently with idiopathic chronic pancreatitis.

he mentioned the drink, and I said 'you have to believe me, he doesn't drink'. I suppose if they found drink a problem...that was easier for them (Family member – Wife)

Additionally, the younger men in the study whose alcohol consumption did not 'fit' with the general pattern of chronic pancreatitis were informed that they were 'unlucky'.

he thinks definitely it was just a very, very bad reaction to alcohol
(Participant 4 – Interview 1)

you were told that you should not drink alcohol and that when God was giving out the pancreas he gave you a bad one (Participant 5 – Interview 1 notes)

However, several others who considered they had abused alcohol over a period of years accepted the explanation.

they told me it was purely alcohol related and I would have accepted it for the amount I was drinking (Participant 3 – Interview 1)

Because they had little or no knowledge of the condition at the point of diagnosis the participants were, to a significant degree, passive recipients of information with doctors controlling how much and what information was imparted.

I even asked the doctor who I spoke to, and again he didn't seem to have any information for me and I don't know what to expect, literally (Participant 11 – Interview 1)

Many felt the explanations did not provide an adequate construction of why they developed the condition or why it was progressing in the manner it was.

no-one has told me exactly why my pancreas has decided to continue the progression of the disease even though I'm not drinking (Participant 7 – Interview 1)

I would have liked to have been informed more why it attacked me as it did...not just 'avoid this' and 'avoid that' but the reason why (Participant 13 – Interview 1)

All participants reported being unable to recollect accurately any additional information they were given at the time of diagnosis. In Kralik et al's (2001) secondary analysis this was attributed to the shock and distress of being diagnosed. Although this was not evident in the participants' accounts, it may be pertinent that all, except one, were hospitalised at this time and some were critically ill.

At the point of discharge from hospital following diagnosis, participants' reports of what they 'knew' about the condition varied. Their accounts demonstrate considerable variation in the amount and depth of information provided about the management and treatment of the condition. All, except two women, said they had been informed that they could no longer consume alcohol and were aware that to do so could induce further acute events: 'they did say if I drank again it would happen again' (Participant 11 – Interview 1).

By implication, several assumed that if they abstained from alcohol, the condition would resolve.

he had no information, so he thought 'oh I had chronic pancreatitis in hospital but I don't have it anymore' (Family member – Wife)

Whilst alcohol abstinence formed the central tenet of the management information provided by doctors, additional advice was given by dieticians and, in one hospital, by the clinical nurse specialist. For those who were referred to or had access to these healthcare professionals, the experience was positive, with particularly useful information being provided verbally and in written form by the dietician.

the dietician explained to me about the use of creon...and that satisfied me a lot (Participant 13 – Interview 2)

Some participants reported how they thought the clinical nurse specialist 'goes out of her way to help you' (Participant 6 – Interview 1) and the

provision of her contact details should they have any concerns was appreciated.

Although it is only possible to make the judgement with hindsight, most participants considered ultimately that the information with which they left the hospital was inadequate in facilitating their understanding and management of the condition. It was only through attempting to assimilate chronic pancreatitis into their everyday lives that its implications became evident. For example, for most, despite following the management advice, symptoms either did not resolve or recurred. At this point participants' information seeking became more active, but was primarily through further medical consultations.

Doctors were seen as the major resource for information about diagnosis, treatment, prognosis and side effects, a finding that is also supported in other studies (Fridfinnsdottir, 1997; Mills and Sullivan, 1999; Mills and Davidson, 2002; Andreassen et al., 2006; King et al., 2006). However, participants reported qualitative differences in the information with which they were provided. An important factor was their perception of the doctor's expertise. One man represented most participants' view when he said of his treating consultant – 'very lucky...got the best man in the country, best man in Europe they say now' (Participant 8 – Interview 3). Interestingly, their perception of expertise was inextricably linked with the interpersonal communication skills of the doctor.

he'd instil confidence in you because he's very confident...you think, 'well I must be in the best hands' (Participant 5 – Interview 2).

he is a beautiful person. You'd put your life in his hands because he kind of instils so much trust. He's lovely (Participant 9 – Interview 1)

This perception of feeling 'lucky' and being in awe of the consultant's expertise was also a finding in Mills and Sullivan's (1999) study of those with operable oesophageal cancer. In the present study, the consultant was deified to a certain degree because of the perception that despite the nature of

chronic pancreatitis, he could improve their lives. Participants also valued doctors who listened and addressed their concerns.

if you asked him a question at least he'd talk to you, he'd explain to you (Participant 8 – Interview 1)

I actually found it very easy to talk to (consultant's name) and the team, and that makes such a difference (Participant 11 – Interview 1)

As a result participants formed 'attachments' to specific doctors and disliked seeing 'strangers'.

most of the time I'm seeing somebody for the first and last time...unless it's (consultant name) it's really very chaotic – in fact it's pretty pointless...all they are trying to do is ask me questions to get up to speed on my file which they've looked at two minutes before I've walked into the office – I know they're kind of winging it (Participant 1 – Interview 2)

I'd rather go to see him because he's my doctor...the other one...she doesn't know anything about you...I feel they wouldn't have any interest in you...at least if you go to the doctor you've always been going to...he knows what (Participant 2 – Interview 2)

A further factor was if the doctor was seen to be contradicting or challenging information they had received from others.

she said to me, 'there's an awful mess inside there', and I said that to the understudy and she said 'no there is not' and I said 'well (doctor's name) said there was and you're saying there's not, who knows what? (Participant 8 – Interview 1)

This reflects Rees and Bath's (2000) conclusion that contradictory information is partly a consequence of a lack of continuity and different professionals not knowing what the other was doing. The difficulty for patients is that

contradictions or inconsistencies make them feel uncertain and confused (Mills and Sullivan, 2000; Hummelinck and Pollock, 2006). Therefore, as the consultant was a constant, most expressed the desire to see him.

When participants expressed a dislike of a doctor or other healthcare professional, it was almost exclusively related to his or her perceived interpersonal skills and the response and attitude that was conveyed. Failure to listen or be taken seriously was also identified as a source of anxiety and dissatisfaction by many of the respondents in Coyle's (1999) grounded theory study of dissatisfaction with healthcare (n=41).

I ended up having a big argument with this doctor that I don't know... that I never met. He was never to do with my case before
(Participant 5 – Interview 2)

Two participants also identified that they learned about aspects of their condition through overhearing healthcare professionals.

they think it's (pseudocyst) over 3cms now – that's what they were saying at the end of the bed – they weren't telling me – I only heard them saying it (Participant 5 – Interview 2)

Although the participants did not specify that this upset them, their demeanour when relaying these incidents implied that they were dissatisfied at their exclusion. When referring to participants in their study who overheard negative aspects of care being discussed by doctors, Mills and Sullivan (2000) suggest it is a matter of basic professional practice and should not occur.

In addition, participants reported that information provision by some healthcare professionals was reactive, that is, they answered questions that were posed but did not volunteer information other than that which was sought.

like I have to ask what the results of my tests were...I did the ultrasound – I said, 'did you get the results?' 'Yeah' and I says,

'there you go – you have the results but you're not telling me'
(Participant 12 – Interview 2)

This finding was also evident in Mills and Sullivan's (2000) descriptive study (n=7), where participants indicated that if they did not ask questions they would not be told. The difficulty with such an approach is that it is based on the assumption that the patients know what questions to ask.

Participants also said that the nature and length of hospital outpatient consultations precludes questioning.

I know they're very busy, professional people and all but I would have like to have sat down and talked to him like I'm talking to you
(Participant 13 – Interview 1)

Moreover, where alcohol had been implicated in the diagnosis healthcare professionals' attitude of disbelief about alcohol abstention tended to compound the reluctance to ask questions or raise issues. The findings of Chapple et al's (2004) study of people with lung cancer, where, regardless of their smoking habit, participants felt they were blamed for their 'self-inflicted' condition, resonates with some of the accounts of those in this study.

Congruent with the above findings, a focus group study of 8 women who had breast reconstruction highlighted that interpersonal relations and technical skills are both highly valued by patients (Wolf, 2004a). However, Coulter's (2002) article reported that studies found 'humaneness' to be the most highly rated aspect of care with 'competence/accuracy', 'involvement in decisions' and 'time for care' being the other most important themes

Several participants also believed that some of the healthcare professionals with whom they consulted, particularly General Practitioners, had an insufficient knowledge of the condition and were only consulted if necessary.

your average GP isn't clued into it either...it's not something they are looking for or something they come across very often
(Participant 1 – Interview 1)

The participants' confidence in doctors was tested when information they received was found, subsequently, to be ill-advised or incorrect.

he said something about if you keep it up then you wouldn't be able to have children...I even said that to a few doctors since – and one thing has not got to do with the other so where he was getting his information (Participant 5 – Interview 2)

That some healthcare professionals were deemed to have inadequate knowledge has been identified in studies of a range of conditions (Mills and Davidson, 2002; Starke and Möller, 2002; Wolf, 2004b; Wolf, 2004a; Hughes et al., 2005) and combined with the attitude and approach of the professionals tends to make patients uneasy and more disinclined to ask questions.

In this study, there was some evidence that participants' and healthcare professionals' lack of knowledge had negative consequences. For example, one man was not prescribed pancreatic enzyme replacement therapy until his seventh admission to hospital in a period of one year.

the seventh (time) they sent me home is when they gave me the Creon and since I've started taking the Creon I haven't looked back (Participant 10 – Interview 1)

Another young man was prescribed pancreatic enzyme replacement therapy for one month but never informed whether he should return for a further prescription. Yet another, who had pancreatitis-induced diabetes mellitus said:

I asked when I was going (home) would I be a diabetic...they didn't think that I was going to be...so I was told not to take medication or they didn't give me medication for diabetes and didn't say I was a diabetic (Participant 2 – Interview 1).

Several of the participants expressed that although they valued verbal consultations with healthcare professionals, supplementary written

information about the condition and what to expect would have been useful. All reported that information in written form was not available to them.

there's no actual leaflet there to say, pancreatitis is caused by this...what to avoid or what to try and avoid...there's nothing there
(Participant 13 – Interview 1)

The potentially important role written information can play when used as an adjunct to professional consultation has been highlighted in the literature (Mills and Sullivan, 1999; Coulter and Ellins, 2007). However, some warn that the content, presentation, comprehensiveness and relevance of written information is a significant consideration in determining usefulness and acceptability to patients (Coulter et al., 1999; Mills and Davidson, 2002). According to Coulter et al (1999) few materials meet the need for information as identified by patients.

Although no studies could be located that examined information provision for people with chronic pancreatitis, others have proposed that it is one of the components of social support (Fridfinnsdottir, 1997; Rees and Bath, 2000; Starke and Möller, 2002; Andreassen et al., 2006; Hummelinck and Pollock, 2006). In some frameworks of social support it is known as cognitive support and is said to help people define, understand and cope with challenging events (King et al., 2006). Thus, healthcare professionals who provide accurate and sufficient information enable those in their care to begin to mobilise coping resources (Fridfinnsdottir, 1997; Shaw, 1999; King et al., 2006). However, the accounts of the participants in this study indicate that the provision of information is mediated by the perception of their interpersonal relationship with healthcare professionals. King et al (2006) contend this is related to an aspect of cognitive support where feeling known and being understood or simply being listened to has an empowering effect. Therefore, central to information provision is the manner in which it is imparted and received. It appears then that where participants judge healthcare professionals to be skilled in communicating information, they are more likely to be satisfied. Conversely, poor communication appears to influence perception of the quality of the information being imparted.

Sourcing

Regardless of whether or not the participants were satisfied with the information provided about their condition and its implications, most also sought information from other sources. The primary motivation appeared to be to gain knowledge about chronic pancreatitis, construct explanations for why they developed it and establish if there were strategies that may be beneficial in managing it. These factors are consistent with reports of other studies and literature reviews that have examined the purpose of information seeking (Mills and Sullivan, 1999; Andreassen et al., 2006; Coulter and Ellins, 2007) and are consistent with what Lazarus and Folkman (1984) define as problem-focussed coping strategies.

Internet

For those who had access, the internet was a key resource. Whilst the five participants who regularly used the internet found some information useful, they felt it was important to be able to discriminate between the quality of the information and the trustworthiness of the websites.

I'd have the experience about how to find good quality information on it (internet) but you know the average patient who doesn't have medical interests they're bound to be lost in Ireland I would have thought (Participant 1 – Interview 3)

the only ones that I entertain are the ones that have some relation to a recognised institution or even personally written by someone with credibility (Participant 4 – Interview 3)

Despite their perceived ability to be able to do this, these participants found some information conflicting or confusing.

it's been hard work, researching and, just finding...it's actually all come to nothing because you get told so many different things (Participant 4 – Interview 2)

Furthermore, one woman highlighted what she perceived were the 'dangers' of the internet.

when you know nothing about medicine and you look up the internet...you get yourself in a knot because you read things (Participant 7 – Interview 2)

To some extent, confusion was compounded when information gleaned from the internet was at odds with that being provided by healthcare professionals.

I'm still caught between what I've read and what the specialists has told me (Participant 4 – Interview 2)

Only one participant mentioned accessing patient-based websites or blogs. However, their focus tended to be on the debilitating aspects of chronic pancreatitis and he did not consider this a positive experience in learning how to live with the condition.

Although the internet has been deemed to be a useful tool for learning (Ziebland, 2004; Coulter and Ellins, 2007), others have reported that the quality of information available varies considerably (Ziebland et al., 2004; Andreassen et al., 2006). Thus those who may not be able to filter and discriminate between what is reliable or relevant could not only be confused but also misinformed.

Family and friends

For two participants family members and friends with medical knowledge were an important source of information about chronic pancreatitis but also was a means of verifying symptom experience and coping strategies to manage them.

initially it was from my dad...he knows the anatomy...so he really knows how the pancreas works, so I got a lot from him. My mum as well, now my mum's been good, she has a slightly different view. She has a carer's view (Participant 4 – Interview 2)

Participants also learned about aspects of pancreatitis through hearing 'stories' of others within their social world and drawing parallels with their own situation. Generally, these lay representations of pancreatitis, although not

always complete or correct, had the effect of portraying the seriousness of the condition.

I wouldn't have been aware of what pancreatitis was up until 1990. But since then the amount of people I know that died as a result of it (Participant 3 – Interview 3)

he had pancreatitis 25 years ago...he was told keep drinking and you'll die...he packed it in...I thought I was bad but he was worse than me with alcohol (Participant 8 – Interview 1)

In studies of information needs of patients, primarily within the field of cancer, findings differ as to the extent that families and friends are used as sources of information (Mills and Sullivan, 2000; Rees and Bath, 2000; Mills and Davidson, 2002). To a certain extent, this can be explained by the 'types' of cancer diagnosis. For example, in one study the participants were diagnosed with oesophageal cancer (Mills and Sullivan, 2000) about which less is known within the lay community than others such as breast, prostate or gynaecological cancers (Rees and Bath, 2000; Mills and Davidson, 2002). Similarly, the small number of participants in this study who were able to utilise family and friends as a resource is indicative of the lack of knowledge of chronic pancreatitis within the general population.

Books/articles/ mass media

Apart from the internet, participants reported that there was little published 'lay' material available on chronic pancreatitis. Several participants tried to purchase books or access materials through the library but did not meet with much success.

the lay person's medical books was pancreatic cancer...the chronic pancreatitis thing didn't show up (Participant 9 – Interview 1)

Similarly, information or knowledge from mass media such as newspapers and magazines was not available although four participants made reference to medical television programmes that were not about chronic pancreatitis but which stimulated associations with their own illness experiences.

Fellow patients/support groups

Only one participant reported that whilst hospitalised, healthcare professionals arranged for him to meet with a fellow patient who also had chronic pancreatitis.

he sat on the bed and he spoke to me, and he told me everything...it just left my mind at ease that what I was going to go through and he was told even in ten years time, no matter how well you feel, you still can't drink (Participant 2 – Interview 1)

Although no general implications about the benefits of peer support can be drawn from one participant's experience, Isaksen and Gjengedal (2000) (n=56) and Isaksen et al (2003) (n=1009) found that fellow patients mean a lot to each other and are the most underused resource in hospitals. Although they found that some patients had negative experiences, for most it was overwhelmingly positive. Fellow patients were seen to be able to provide a perspective and understanding of the illness that was pertinent as well as being able to present a tangible and realistic representation of the future (Andreassen et al., 2006).

Several of the participants also made reference to the need for a patient support group. This need for contact with others with chronic pancreatitis was evident during data collection when they often asked about the experiences of other participants in the study.

if I had a bit more time and energy I'd set up some sort of support group in Ireland, put up a website and link it...there's plenty of decent resources out there you could pull together. There are good support groups for Americans and Brits but there's none for Irish CP patients that I've come across (Participant 1 – Interview 3)

I'd love to speak to somebody that actually is in the same situation as me (Participant 6 - Interview 1)

Although reports of user and support groups as sources of information vary, several studies found that patients need contact with others in the same

situation as themselves (Mills and Sullivan, 1999; Mills and Davidson, 2002; Isaksen and Gjengedal, 2000; Starke and Möller, 2002). Therefore, whilst support groups may not always be a primary information resource, they do appear to be important not least in terms of providing emotional support.

Some studies report that information gleaned from alternative sources facilitates interactions with healthcare professionals by enabling patients to present themselves as competent (Hardey, 1999). Although participants in this study did not specifically refer to how additional information influenced their interactions with healthcare professionals, it can be inferred that it had some impact. According to Ziebland et al (2004) there was a suggestion in their study of 175 people with cancer, that finding out about their condition enabled patients to plan for the consultation and identify appropriate questions. Having undertaken one's own research also makes it possible for patients to monitor the treatment and management options being presented by healthcare professionals (Starke and Möller, 2002; Hummelinck and Pollock, 2006). Ultimately, information can change the nature of the interaction between patients and their healthcare professionals, albeit not always in a positive way (Andreassen et al., 2006).

Unknowing

Over time, participants came to know the nature of chronic pancreatitis but at the time of the study, there were still gaps in their knowledge about the condition and its management. Some did not know the function and location of the pancreas and few knew the extent and type of damage that had occurred.

I don't know why chronic, I haven't really been told why it might develop from acute to chronic (Participant 4 – Interview 2)

I actually felt stupid asking you where the pancreas was.
(Participant 6 – Interview 2)

Three participants did not understand the action of the pancreatic enzyme replacement therapy and whilst they were taking the tablets, they were doing so in a way that rendered them ineffective.

I was taking it (creon) wastefully as well because I was taking it every day without actually eating anything...because I didn't know...it's useless taking it if you're not after eating anything (Participant 5 – Interview 2)

I take 30,000 (creon) in the morning, 30,000 around three and 30,000 around ten-ish. I'm just working the way they used to work off me in the hospital (Participant 6 – Interview 3)

One man who was diagnosed with chronic pancreatitis as a result of hyperlipidaemia did not know his cholesterol level and said it had never been mentioned during his recent admission. In respect of treatment options, most participants were aware that surgery was a possible alternative to conservative treatment but only four knew the conditions under which it might be performed.

we were told it (surgery) was absolutely the last resort (Family member – Wife)

the damage was so widespread, it's like this rosary bead effect up the middle of the pancreas and that there is no specific area that I could say 'well, if I fix that it'll work', because it's too widespread – it's all or nothing – this was the way I read it (Participant 7 – Interview 1)

Similarly, participants demonstrated varying levels of knowledge about their long-term prognosis. Although all knew that there was no cure for chronic pancreatitis and that the condition was a life-long one, few grasped fully the meaning of its progressive nature. This was evident by their lack of understanding of why symptoms recurred despite adhering to treatment regimes.

I don't know whether it's the lifting or the long hours I did, I don't know what triggered the attacks off again (Participant 10 – Interview 1)

Furthermore, participants did not appear to have any knowledge of long-term complications associated with chronic pancreatitis. Only those who had been suspected of or diagnosed with diabetes mellitus knew of its relationship with chronic pancreatitis. Similarly, those who had developed pseudocysts were aware they were a complication of the condition but did not understand their pathology. Only one participant was aware of the increased risk of developing pancreatic cancer.

However, even those who understood the concept of a progressive illness did not know the potential course of the condition or their life expectancy.

I mean it's impossible to make long-term career or family plans...because you just don't know what the hell is going on
(Participant 1 – Interview 3)

It is evident from these accounts that the participants' 'unknowing' was in part related to their perception of information provision. Whilst sources of information other than healthcare professionals can provide a general picture about chronic pancreatitis and its management, participants wanted information tailored to their own situation, a finding supported by several other studies (Fridfinnsdottir, 1997; Rees and Bath, 2000; Paterson, 2001a; Andreassen et al., 2006; Hummelinck and Pollock, 2006). Whether this had simply not been provided or whether participants could not absorb or retain the information or a combination of both can only be speculated upon given the self-report nature of the study.

Regardless of the reasons, participants' overall understanding of chronic pancreatitis and its management was lacking and had implications for self-care and day to day management. This finding is supported in Nagelkerk et al's (2006) study, where lack of knowledge was found to be the highest ranked barrier to self-management of diabetes.

However, there was a subtle distinction in the current study between those who knew they lacked the requisite information or knowledge and those who did not or were misinformed. Being misinformed, having outdated or incorrect information, knowing little about their illness and medication regimes in

particular, have been identified as clear issues for healthcare intervention in order to maximise support and self-management (Haugbølle et al., 2002; Nagelkerk et al., 2006; Landreneau and Ward-Smith, 2007; Gordon et al., 2007). As is evident from the findings of this study, whilst information provision is central, it is equally important to assess the patient's understanding of what has been imparted.

It was during the phase of coming to know chronic pancreatitis that participants also developed awareness of their irrevocably changed lives. As indicated earlier, although the onset of physiological disruption marked the beginning of a transition from health to illness, the participants were not aware of it. This represents a challenge to Kralik et al's (2006) contention that awareness is necessary in order for transition to occur. The findings of this study do suggest however, that awareness is necessary in order to recognise the change to one's life, which in turn acts as a motivator to engage with the process of transition, a view supported by Meleis et al (2000). Engagement is seen as an essential property of transition and, although the levels of engagement varied among the participants in this study, the process of coming to know chronic pancreatitis essentially marked the beginning of the realisation of the need to construct a new reality.

6.2.2.2 Explaining

This final theme in coming to know chronic pancreatitis concerns the participants' individual constructions of why they developed the disease and why, in their view, the symptom pattern and illness course progressed as it did. Initially, many accepted the bio-medical explanations of why they developed the condition. However, as their medical and experiential knowledge developed they began to question the adequacy of these explanations both in terms of causation and continued physiological assault. While their subsequent constructions were ordered around medical explanations, they were overlaid with accounts of social and personal life event factors that they believed triggered the onset of the condition and contributed to continued assaults. For the most part, these explanations were constructed through the processes of attributing and paralleling.

The most commonly cited factor was stressful life events. For example, one participant who had been told that alcohol was a causative factor contested this reasoning when she cited that at the time of her first attack she had not consumed alcohol for two years. Although she subsequently recognised that the pancreas may have already been damaged without her knowledge, she attributed the onset of chronic pancreatitis to a significant and stressful life event.

Stress was also associated with the onset of pain or worsening of symptoms. Several participants cited incidents where, in the absence of other triggering factors, feeling stressed about family, home or work was more likely to be associated with worsening symptoms, particularly pain.

I've noticed that the pancreatitis seems to me to come on worse when I'm in emotional situations that are highly charged and when I have a lot of stress (Participant 3 – Interview 1)

I suggested that it was stress related – I know it is, I know these episodes are (Participant 7 – Interview 1)

The participant with idiopathic chronic pancreatitis and his family searched for possible causal factors and determined that his diet in previous years may have played a part.

It could have been the food that he was eating for all those years...all fatty foods...that could have contributed to what he has now (Family member – Wife)

The mother of one participant also offered severe allergic reactions to certain foodstuffs as a possible contributing factor. This hypothesis was located in her belief that his alcohol consumption was no different to any young man of his age and some other factor must be implicated.

this was in the few months before he got acutely ill and it seemed like it was his body's way of not coping. It was a profound and weird reaction to Chinese food (Family member – Mother)

Other propositions reflected the incorporation of medically based theories within the participants' social and family context. For example, one participant highlighted the possibility that a hereditary factor may be noteworthy as two members of a previous generation of his family had chronic pancreatitis. Others cited alternative explanations such as a 'rogue gene', the use of 'kerosene' heaters and having a 'bad' pancreas. Yet another argued that the absence of any sign of liver disease meant that alcohol could not be the sole causative factor.

they never diagnosed a liver problem, I haven't got a liver problem and I still don't have a liver problem (Participant 2 – Interview 1)

Participants' reasoning was commonly supported by a process described here as paralleling, where they recounted stories of people they 'knew' who, on the basis of their alcohol assumption, should have chronic pancreatitis but did not.

but neither his pancreas nor his liver are damaged and he's 56 and he would have been drinking steadily from when he was eighteen. And then home drinking of course...and a litre, litre and a half a day of whiskey. And when he came out of hospital...he got the all clear and everything (Participant 11 – Interview 1)

Conversely, they also cited those who had the condition and had never consumed alcohol as further evidence that it could not be a sole basis for its manifestation.

I've met several people that have had it and still have it and never drank alcohol (Participant 14 – Interview 1)

These participants' assertions reflect their beliefs that their pattern of alcohol consumption could not be the only reason for the development of chronic pancreatitis. Furthermore, it appeared that citing other possibilities was a form of self-assurance that they were not entirely responsible for the onset of the condition.

In a study of women with chronic obstructive pulmonary disease O'Neill (2002) found that her participants also had rich representations of the cause of their illness that extended beyond and elaborated upon the original medical cause. Although 18 of her 21 participants had been smokers for an average of 42 years, only 8 felt it was the only cause and bacterial infections, factory working, tuberculosis, passive smoking and stress were among the reasons mentioned. Similarly, King (2002) found stress was alluded to as a contributing factor to the onset of myocardial infarction in 17 of her 24 participants.

These findings reflect the view that patients' illness constructions essentially occur in a social context and differ from the more mechanistic view of disease held by healthcare workers (Wellard, 1998; Thorne, 1999; Bury, 2001). It is evident, however, that in constructing explanations of cause and continued disruption, the participants do not disregard medical theories or knowledge but, as Bury (2001) claims, offer lay 'correctives' arising from their individual situation.

Despite their convictions, participants presented these ideas as tentative propositions. This seemed to arise from an underlying sense that they would not 'fit' with the dominant discourse of disease causation. As a result, few discussed their beliefs with healthcare professionals and when they did so the response reinforced the point made earlier that 'lay' beliefs would not be countenanced or taken seriously.

basically given me the impression that the only thing that has caused my illness is alcohol. It has nothing to do with diet and they kind of give you the impression that anything you might suggest is like voodoo or witchcraft (Participant 4 – Interview 2).

Nonetheless, what was important subsequently was that these constructions influenced, to some extent, how the participants approached the day-to-day management of their condition.

6.2.3 Summary

Coming to know, as it is described by the participants in this study, is a complex process that marked the beginning of the health/illness transition from well person to a person who lives with chronic pancreatitis. Through 'coming to know disrupted body' and 'coming to know chronic pancreatitis' participants became aware of their permanently altered lives. Initially, participants were unaware that they had begun such a transition. In the pre-diagnostic phase cognitive appraisal and reappraisal of the threat associated with disrupted body led to mobilisation of problem-focussed coping strategies to identify its source. However, at this point the significance of their illness for their future lives was unknown. With diagnosis, came awareness and the beginning of engagement through the process of finding out. Engagement was evidenced by the movement from passive recipients of information to mobilisation of coping strategies such as actively seeking information and knowledge from a number of sources. However, throughout coming to know, factors such as personal values and beliefs about illness and illness behaviour, situational factors and relationships with healthcare professionals were deemed important mediators in facilitating or constraining their coping. Coming to know was ultimately significant, as it constituted the foundation on which the participants based the subsequent management of their chronic pancreatitis.

6.3 Adjusting/Managing

This section is concerned with a number of complex, interrelated processes that define how the participants and their families manage and adjust to living with chronic pancreatitis. It includes the coping strategies adopted and the resources mobilised as a result of coming to know the condition. Thus, there is a direct relationship between coming to know chronic pancreatitis and adjusting to living with the condition. Although there is a sense of progression from one phase to the next it is not strictly linear, nor are there clear boundaries between them as is suggested by the sequential presentation in this report. In reality, participants continue to come to know through everyday living with the condition and as they glean new knowledge and information. As their understanding increases, their appraisal, management and response to the condition adjusts and changes. Therefore, coming to know and adjusting can be said to have a synergistic relationship.

Adjusting/managing encompasses the daily living activities participants engage in to modify or minimise the impact of the symptoms of chronic pancreatitis and maintain or maximise their health potential (Figure 6.2). Although in the initial stages following diagnosis, these were founded mainly on information gleaned from professional sources, with experimentation, trial and error and testing participants increasingly adopted strategies based on self-knowledge and bodily responses. The principal themes include 'handling the pain', 'modifying lifestyle', 'self-monitoring', 'emotional coping', 'drawing on social resources' and 'interacting with the healthcare system'. 'Handling the pain' is presented as a discrete theme because of the overwhelming emphasis on its management. 'Modifying lifestyle' explicates adjustments particular to this group and include the sub-themes of 'abstaining from alcohol', 'adjusting diet', 'prioritising demands' and 'struggling to live well'. Continuous 'self-monitoring' provides participants with feedback on their body's response to their illness and is an important contributing factor in how they make decisions.

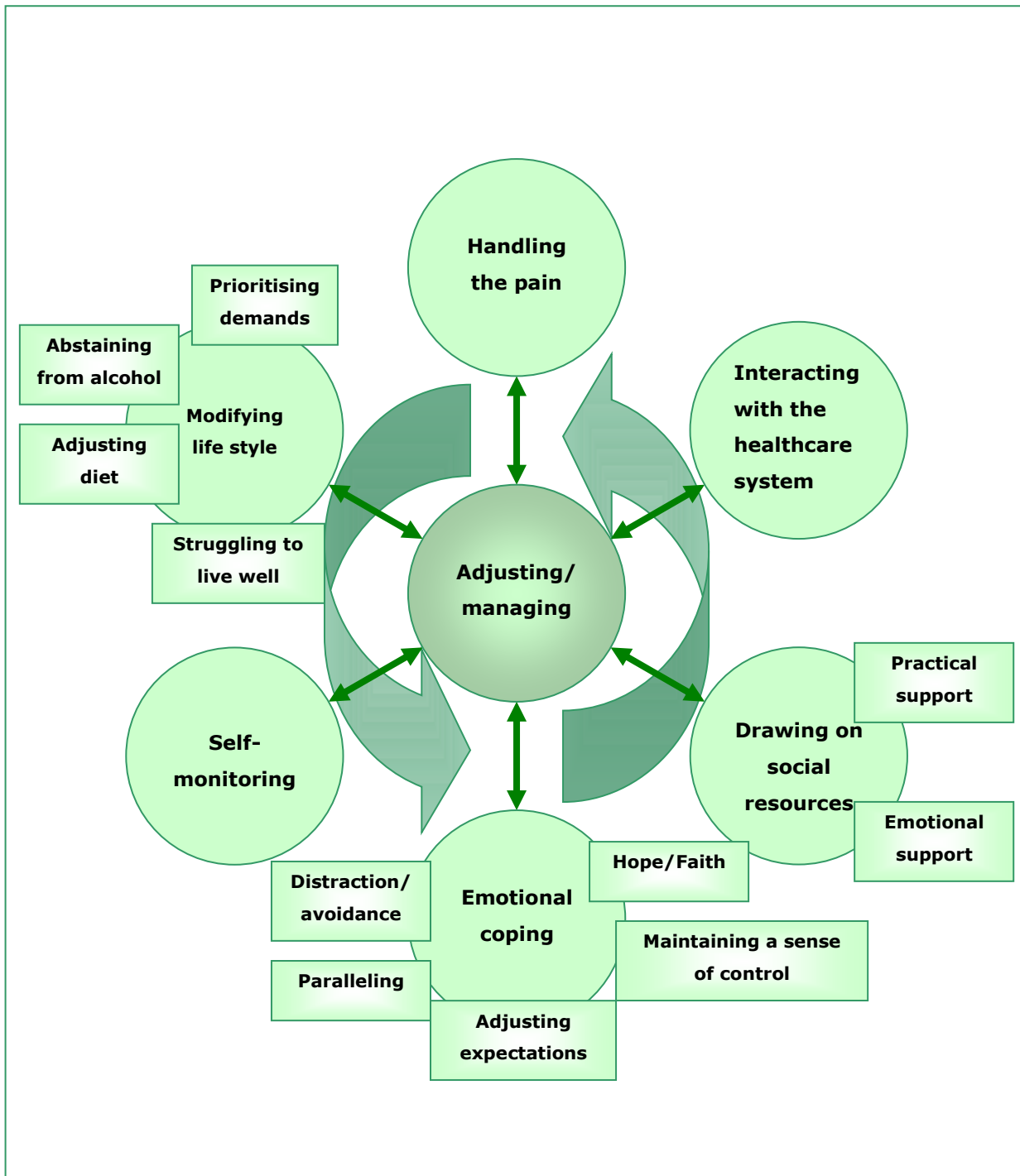
Adjusting/managing also includes a range of coping strategies expressed here as 'emotional coping' that incorporate the participants' efforts to regulate their

emotional responses to illness. 'Emotional coping' includes the sub-themes of 'adjusting expectations', 'maintaining a sense of control', 'distraction /avoidance', 'paralleling' and 'hope/faith'. The strategies adopted vary across participants and alter depending on the individual's changing perception of the impact of the illness on their lives.

'Drawing on social resources' is explicated through the sub-themes of 'practical' and 'emotional' support arising from the participants' social network of family and friends and, to a lesser extent, professional and state agencies. Although largely facilitative, corresponding constraints associated with expectations and limitations within their social network are also presented. The final theme of 'interacting with the healthcare system' outlines how participants accommodate regular and necessary contact with the healthcare system for the purpose of ongoing monitoring and being treated. This includes how they develop strategies for managing what they perceive as shortcomings within the system.

An important point is that there are variations in the level of engagement with adjustment across the participants with some being more active than others. On the surface, this seemed to be related in part to the length of time since diagnosis with those who had been diagnosed some years previously having achieved a more stable outlook. Those recently diagnosed are still experiencing significant fluctuations in symptoms that appear to impact on how they are adjusting.

Figure 6.2: Adjusting/Managing



6.3.1 Handling the pain

Given its intrusive nature and its implications for all other activities of living, handling the pain of chronic pancreatitis occupies a central position in the self-care strategies adopted by the participants.

Prescribed and over-the-counter analgesia form the mainstay of management but other medications such as pancreatic replacement enzymes and proton

pump inhibitors prescribed for gastrointestinal disturbances are also considered by some participants to be helpful in the prevention and management of pain. Three participants have tried alternative or unorthodox therapies although their use is not regular or sustained.

Since the frequency and intensity of pain differs considerably between participants, there is a wide variation in the type and amount of analgesia being used. Nonetheless, all participants regard availability of some form of analgesia as essential in enabling them to cope.

I have to take the creon and the sevredol and the MST. I can't get through the day without the tablets (Participant 6 – Interview 1)

However, within the limits of their prescription, all participants recounted how at times, they adjust and adapt their analgesic usage. This decision is triggered mainly by the perceived effectiveness or ineffectiveness of the medication or the emergence of undesirable side-effects that compromise their functioning to a level that is intolerable. As they became familiar with the prescribed medication, they experiment with dosages and timings that they believe are more acceptable.

the only killer is if I get a pain and I have to take a tramadol, boom, there's your appetite gone – what I usually do now is eat as much as I can in the morning so if I know it's going to kick off at least I'll have something eaten before it does (Participant 5 – Interview 2)

Whilst many of the participants' actions are directed at decreasing their analgesic use, on occasion they exceed recommended doses and in some instances supplement with over-the-counter medications. At these times, participants are inclined not to report their level of analgesic use to doctors or other healthcare professionals. There is a sense that their actions would not be approved of.

I just went back on the original – I didn't even ring him because he'll go mad because I don't think he likes me messing about with it (Participant 7 – Interview 2)

For some, manipulating analgesic use to control the pain also extends to periods when they are hospitalised.

I brought in my own tablets – just to double the dose...at least I'd doze off or something. If they found out – I wasn't going to tell them – they'd take them off me – if they did I'd tell the wife to bring more in – I didn't give a s*** (Participant 8 – Interview 2)

what I had to do when I was in hospital – it was disgraceful – I had to ring my mother to smuggle in my medication so I could take my own painkillers while I was out there (Participant 5 – Interview 2)

In general, specific consultations with doctors about the effectiveness or side-effects of analgesia are rare. Any discussion tends to occur within the overall context of outpatient follow-up appointments or on discharge from hospital, with the intervening periods being concerned with attempting to find the most efficacious combination of available medication. Although it was unclear from the data why this was the case, one participant highlighted what he felt was the unsatisfactory approach to his pain management.

first of all they put me on Tylex for 6 months, then Zydol for 6 months, then Dicene for 6 months, then the Buprenorphine for 6 months...it's been kind of a hit and miss approach (Participant 1 – Interview 1)

Others articulated that reporting poor analgesic control results in over-medication, which compounds undesirable side-effects.

I asked her 'please take me down off some of this medication'. 'Try me on the Zydol again – even give me a morphine that's lower' (Participant 7 – Interview 2)

from day 1 he's been telling me that I'm overmedicated – he says, 'you're taking way too much stuff'. I said, 'I know that but...' this is not me...I'm not the one...'I want this and I want that'. It's just

really, really hard to find anything that agrees with you (Participant 5 – Interview 2)

Furthermore, where their concerns about over-medication are not adequately addressed participants resort to their own actions to address their concerns.

I find if I use the medication all the time that it doesn't work...if I leave it alone, or if I take, say, two Solpadeine or something it dulls it slightly. And that's ok...because then, if I get away with the Solpadeine for a couple of days as it gets worse, well then the Zydol will work for me (Participant 3 – Interview 2)

These findings indicate that the participants in this study make active decisions about their use of analgesia. This is supported in several studies related to the use of antihypertensives (Benson and Britten, 2002), diabetes (Thorne et al., 2003), asthma (Raynor et al., 2004) and cardiovascular medications (Gordon et al., 2007) where everyday experience of living with illness, general beliefs about medication use and the perceived harm, efficacy or safety of specific drugs are influential in determining the level of adherence to medication regimes. In one qualitative study of chronic pain management in 72 elderly persons (Lansbury, 2000), medication use was a non-preferred strategy for pain management and was avoided for fear of addiction, noxious side-effects or because they were ineffective. This corresponds with the views of the participants in this study that drug use is ultimately harmful. However, this has to be balanced in each individual's situation against the perceived benefit of pain alleviation. Participants calculate the risk of analgesia use against unwelcome and undesirable side-effects and disrupted functioning and attempt to achieve a tolerable compromise. At times, however, the risk of uncontrolled pain is deemed more pernicious and results in their beliefs about medication harm being suspended. It is on these occasions that participants tend to over-medicate.

That participants choose not to disclose their over-medication because of a fear of disapproval is supported by Paterson et al (2001). Whilst there was little evidence in the participants' accounts that this belief is a result of interactions with doctors, their dialogue regarding analgesia being withheld in

hospital and the emphasis in pharmaceutical literature on not exceeding recommended limits may contribute to this conviction.

Despite the emphasis on analgesia in the handling of pain, participants discovered through experience, several strategies that they believe ameliorate or prevent pain or are useful adjuvants.

All participants reported that stopping food intake during times of escalating pain is useful in addition to other measures such as analgesic use. Furthermore, several believe resting ameliorates pain whilst others feel that physical exercise such as cycling or walking helps.

I'm tired and stressed out and that if I rest at all I'm getting good days you know pain is minimal (Participant 3 – Interview 1)

I got into cycling a lot and it really, sometimes if I was very ill, I wouldn't feel anything while I was cycling (Participant 4 – Interview 3)

This is consistent with the findings of other studies where physical activity as well as rest could induce, exacerbate or relieve pain (Breen, 2002; Jerlock et al., 2005).

In keeping with the findings of a meta-analysis cited by van Esch et al (2006) none of the participants, in this study, reported pancreatic enzyme replacement therapy as being of benefit in the relief of pain. However, some state they find it to be a useful preventative measure whilst others cite proton pump inhibitors such as omeprazole or anti-dyspeptic medication as helpful. These findings have some tentative theoretical support since in both cases inhibition or reduction in the stimulation of the pancreas can result (Hussain and Karnath, 2005; van Esch et al., 2006).

As stated above, three of the participants have tried alternative or unorthodox treatment for preventing and handling pain. One participant, who is trained in auricular acupuncture, declared his acupuncturist facilitated management of his pain.

I've a lot of faith in him and in fairness to him he got rid of my pain for over two months because he's a full body acupuncturist (Participant 3 – Interview 2).

Two other participants take antioxidant therapy having read of their potential beneficial effects on enzyme production, fat absorption and pain levels. One participant particularly referred to the perceived benefits of turmeric (curcumin). Although limited, there is some support in the literature for these participants' beliefs. One small scale study (n=20) of the antioxidant effect of curcumin in tropical pancreatitis (Durgaprasad et al., 2005) found a significant improvement on the oxidative stress but there was no effect on pain levels. However, a further randomised, double-blind, placebo-controlled, cross-over trial (n=36) (Kirk et al., 2006) found that combined antioxidant therapy (selenium, betacarotene, L-methionine, and Vitamins C and E) was associated with significant improvement in pain levels. Whilst the benefits of antioxidant therapy as an intervention in chronic pancreatitis are not conclusive, the evidence to date suggests they may have a role in the handling of pain.

6.3.2 Modifying lifestyle

All participants in the study have made life-style modifications, which are largely directed at preventing and minimising the impact of enduring daily disruptions such as intrusive pain, gastrointestinal disturbances and food intolerance, incapacitating fatigue and loss of physical strength. Initially, most felt that modifications were enforced by virtue of the diagnosis but ultimately believe they are positive and beneficial in terms of their overall health.

the fear of the pain makes you look after yourself...it becomes practical, because I can't make the decision to not look after myself anymore. The pain is too great when I don't (Participant 3 – Interview 3)

Yet success in initiating and sustaining the modifications vary and appear to be predicated on the individual's context and situation and to some extent their underlying belief as to whether the changes make any difference.

6.3.2.1 Abstaining from alcohol

Most participants believe, through information gleaned from healthcare professionals that cessation of alcohol consumption is the single most important factor in their self-care. As a result, all participants who were consuming alcohol attempted to stop immediately following diagnosis. Fear of consequences, particularly physiological disruption, was the primary motivator.

what would I be like if I drank? – if you get an attack like that and you don't drink – what is it going to be like if I do drink?
(Participant 2 – Interview 1)

For most, including some who were informed their chronic pancreatitis was alcohol induced abstaining from alcohol was not difficult.

I haven't had a drink in five years – I actually found it quite easy really to be honest (Participant 1 – Interview 1).

However, and as stated in the previous chapter, among this group are those who find social interaction without alcohol challenging because of the cultural emphasis on its consumption. Although social withdrawal seems to be a protective strategy adopted to avoid feelings of exclusion or being different, in some ways it is counter-productive as it exacerbates participants' sense of isolation.

when I used go on a Sunday on this 10 km (walk) I used to have a lot of the pubs along the way and I could hear the jeers of the crowd inside on the match afternoons and it bothered me that I couldn't go in (Participant 13 – Interview 2).

Over time, some participants have actively sought alternative social outlets or social engagement to a level that satisfies their interaction needs. However, those who avoid social interaction because they are unwilling or feel unable to do so are those who are more likely to have reported 'feeling down'.

A small minority of participants who reported a history of alcohol abuse and who found abstinence difficult also experienced some negative emotional responses. Initially, they sought professional help through organisations such as Alcoholics Anonymous.

I went to AA meeting and all that...had a sponsor...I went to the third step – you know the way there is 12 steps with the AA...I was doing great (Participant 12 – Interview 1)

However, despite their efforts, these participants were unable to sustain their abstinence and at the time of the study were no longer receiving help or attending meetings. Although they continue in their attempts to stop drinking, they are more likely to 'take chances' with alcohol. This behaviour seems to be bound partly in their appraisal style where relapsing into alcohol is attributed to a myriad of external factors such as social situations, employment and other people.

I'd only be lying to myself if I said I'd never pick up a drink again cause it only takes one thing...say for your mother to die or something like that and then you'd go back on the drink (Participant 12 – Interview 1)

it's the job I'm in that doesn't help matters a lot either – that's probably why I'm always thinking of drink...it's always in my head about drink because I'm surrounded by it (Participant 12 – Interview 2)

This appears to permit the participants to locate some of the responsibility for their situation elsewhere thus allowing them to present themselves, at least in part, as victims. This was epitomised by one man who declared of alcoholism:

they used to say it was a social disease now they say it's an incurable disease...it's not just a social...they reckon now hereditary (Participant 8 – Interview 1)

In addition, these participants justify their continued drinking by citing the lack of substantive evidence of a direct relationship between alcohol consumption and the onset of physiological disruption. In their view this is supported by their own experiences.

when I got away with drinking – I’m inclined to – ‘will I push it a bit farther to see how much I can get away with?’ (Participant 8 – Interview 2)

I did have one or two drinks then...at a weekend away or something like that or a party and I felt alright after that and I said ‘ah, they’re talking sh**e’ (Participant 12 – Interview 1)

Regardless of their continued difficulties these participants stated that their alcohol consumption has reduced and cited it as a positive change in their lives. Nonetheless, their cognitions and reasoning represent a reluctance to address the problem of their alcohol dependence effectively, which is reflective of avoidance coping (Hasking and Oei, 2002; Moussas et al., 2006). Furthermore, their need to consume alcohol appears to reduce their ability to seek help and address possible alternative solutions.

There is a prevailing view in the chronic pancreatitis literature that withdrawal from alcohol is difficult because of dependency in those with alcohol induced chronic pancreatitis (Gorelick and Robles-Diaz, 2002; Apte and Wilson, 2003; Gullo, 2005; Nair et al., 2007). In this study, the participants’ reported level of difficulty ranged on a continuum from easy to impossible. Those who found it easy or relatively so believe it is because they are not alcoholics. To them, their patterns of drinking were not consistent with that of an alcoholic and the ease with which they abstained from alcohol was evidence in support of their claim.

I’m not an alcoholic, never have been, nothing like it, I’ve seen alcoholics and I know their way (Participant 13 – Interview 1)

it wasn't that I drank heavy but I was a regular drinker. I actually worked with two of them (alcoholics) so I knew myself what an over-dependence on alcohol could do (Participant 14 – Interview 1)

Conversely, those who found it difficult or impossible to stop drinking alcohol propose that this is accounted for by their alcoholism.

'no doubt I was an alcoholic, I suppose still am one, I was detoxed four times' (Participant 8 – Interview 1)

Although their definition of what constituted alcoholism or alcoholic behaviour was not explored, the difference between these participants and those who successfully abstained is a desire or urge to drink alcohol despite the potential or known consequences of doing so. The almost tangible and psychological urge to drink can be attributed, in part, to the existence of the multidimensional concept of craving in addiction (Anton, 2000; Westerberg, 2000; Cutler, 2005; Grüsser et al., 2006).

If you even took out even a glass of Heineken and it's like the mouth would be watering (Participant 12 – Interview 2)

I'd still go into the pub to have a pint of blackcurrant and its still there, 'ah sure, have a pint' (Participant 12 – Interview 3)

Those who drink alcohol regularly but who are not addicted tend not to experience craving on the same level as those who are (Grüsser et al., 2006). Studies of addictive behaviour have long considered craving to be of central importance for the maintenance of addiction (Cutler, 2005; Grüsser et al., 2006). Craving develops after chronic use of alcohol, is a predictor of subsequent alcohol consumption and increases the probability of relapse (Addolorato et al., 2005; Cutler, 2005).

However, according to Zywiak et al (2003) craving is only one of three categories of relapse, the others being 'negative effect' (anger, depression, anxiety) and 'social pressures' (direct and indirect). As indicated previously, participants in this study made reference to both of these factors in relation to

difficulties abstaining from alcohol. Yet, not all participants who reported experiencing these factors relapsed.

miserable all week...all sorts of things going through my head...feel like having a drink but am aware of consequences but so what?
Didn't bother (Participant 13 – Diary entry)

An important point here is the influence of significant antecedents such as self-efficacy, coping strategies and alcohol expectancy on what people do when in high-risk situations (Zywiak et al., 2003; Hasking and Oei, 2004).

Alcohol-dependent persons tend to use avoidant coping strategies such as suppression of problem management or denial and are more likely to see alcohol consumption as a way of coping with stressful situations (Hasking and Oei, 2002; Hasking and Oei, 2004; Moussas et al., 2006). In addition, they are more apt to report positive alcohol expectancies or gains from drinking. They are also inclined to attach blame on external factors, which enables them to reduce feelings of inadequacy, threat and victimisation, possibly associated with low self-efficacy (Moussas et al., 2006).

Self-efficacy is viewed as the individual's judgement of their ability to organise and implement tasks in order to achieve selected outcomes (Holloway and Watson, 2002). In alcohol abuse, self-efficacy expectancies have been related to the individual's perceived confidence and ability to refuse alcohol in high-risk situations (Hasking and Oei, 2002). As the level of alcohol abuse increases the ability to cope systematically decreases (Hasking and Oei, 2004).

Despite the parallels that exist between the literature on alcohol abuse and the participants' self-reports of issues that influence their abstention and/or relapse to alcohol, it would be naïve to suggest that they account totally for their drinking behaviour. Not only is the nature of drinking behaviour highly complex (Hasking and Oei, 2004) but other factors such as personality characteristics that were not explored in the current study are purported to be implicated in vulnerability to alcohol dependency (Moussas et al., 2006). Nonetheless, what the findings of this study do demonstrate is that people

who are diagnosed with chronic pancreatitis and have co-existing alcohol dependence are likely to have a more acute illness trajectory (Gorelick and Robles-Diaz, 2002). Furthermore, the imperative to abstain permanently from alcohol provokes a spiral of repeated abstentions and relapses that can be psychologically and socially challenging.

6.3.2.2 Adjusting diet

All participants made successful adjustments to their diet, primarily to prevent and manage gastrointestinal disturbances and food intolerance. Initial change focused on introducing a low fat diet on the recommendation of healthcare professionals particularly dieticians.

a low fat diet...and we more or less stuck to that...but it didn't really... it helped but.... (Family member – Wife)

Where initial adjustments were unsuccessful participants adopted a range of strategies to identify solutions. Primarily, through experimentation and trial and error, they identified foodstuffs that caused adverse reactions. Although there were individual differences, most identified chocolate and acidic and spicy foods as being implicated.

the things that I cut out are saturated and now white wheat products...that's only because of the amount of pain they have given me in the past (Participant 4 – Interview 3)

I try to stay away from chocolate and things (Participant 8 – Interview 1)

like if I ate certain foods I'd get cramps...stew, coddle – you know the fat content in these – I don't break fats down and sometimes that triggers it off (Participant 14 – Interview 1)

Eventually most have come to know what works for them both in terms of foods that can be tolerated and patterns of eating.

I've sort of made up my own diet...I've been eliminating anything like that caused me to get sick (Participant 6 – Interview 1)

I won't eat willy nilly now...I'll know what I want, I'll know what I have to eat and I'll stick to it (Participant 10 – Interview 3)

Where participants' individual efforts remained unsuccessful, some sought help at their routine hospital consultations. In the presence of weight loss and indicators of malabsorption such as steatorrhoea, most were prescribed pancreatic enzyme replacement therapy, which when taken as prescribed was felt to be beneficial.

if I eat a box of chocolates and I don't take an enzyme I'll pay for it...but I'm pretty religious with the enzymes...I'll take them with every main meal like (Participant 1 – Interview 3)

So I nearly look at what's in the meal and if there's a kind of a mixture of stuff to be broken down...not too big a quantity of stuff...might get away with one (creon). Whereas if there are potatoes, cabbage, bacon and ice cream 'oh, we definitely need two'. I kind of work it on that basis the whole time (Participant 9 – Interview 1)

From the participants' reports it was evident that adjustments to diet are not confined to the perceived necessity of reducing fat intake. Most have attempted to introduce foodstuffs and supplements that are deemed generally healthy – 'I'm eating an awful lot of fruit now that I used not eat' (Participant 8 – Interview 1).

However, one participant in his attempts to palliate his symptoms imposed severe limits on his diet and compromised his nutritional status. This young man was basing all his decisions about foodstuffs on experience alone and even though he was actively addressing his problem he was doing so without the requisite knowledge and support.

'what I was doing was cutting things out that I thought were harming me, and she said 'well, I think at this point you've become more ill because your diet is really limited' and she said 'you can't keep cutting things out because you are going to be eating nothing' (Participant 4 – Interview 2)

As outlined in the previous chapter, the presence of diabetes, or co-existing morbidities, complicate the management of diet in five of the participants. Three of these participants actively manage their diabetes and attain glycaemic control through blood glucose monitoring, dietary control and administration of anti-diabetic medication. If needed, they seek help from their GP or, where available, the diabetic nurse specialist. One woman sought additional support from a slimming club as she felt it provided a diet that was congruent with the aims of glycaemic control.

they work on the GI diet which is perfect for diabetes, just basically high fibre, low fat...I don't really want to lose weight – I just want to get the blood sugars and all back in order. I'm getting more back to my normal. (Participant 7 – Interview 2)

Of the other two participants with diabetes, one woman who has the further complication of a hiatus hernia has a more passive role in her diabetes management with blood glucose monitoring being limited to hospital visits. Since her diabetes is controlled by diet alone, her focus is to avoid foodstuffs that she considers are implicated in diabetes.

there's one thing in my favour anyway with the diabetes, I was never a sweet or chocolate eater (Participant 6 – Interview 1)

It was evident from her discourse that her understanding and knowledge about diabetes is limited to what could be described as a 'lay' conception about its relationship with sugar. Yet, she does not appear to have sought or been given information that would facilitate her self-management. Why this was the case is not clear but there is a suggestion in her dialogue that she tends towards acquiescence in her interactions with healthcare professionals.

The fifth participant with diabetes stated he made infrequent attempts to monitor his blood glucose, did not always purchase his medication and did not always attend to his diet. Although it was evident that this man understands the need for glycaemic control, the complexity of his co-existing morbidities coupled with financial constraints means that at times he chooses to pay for the drugs he considers more important.

I'll tell you even in terms of the medication, I get the painkillers – I have the money for them quicker than I will the glucophage...
(Participant 3 – Interview 1)

Interestingly, where participants lived in a family unit responsibility for dietary adjustments seems to follow traditional lines where the woman, regardless of whether or not she was the 'patient' ensured adherence.

he has spaghettis and he has rices and I'm very particular about what he'll eat and I have the George Foreman...so if there's any fat... (Family member – Wife)

Despite the overall positive changes in diet, most participants spoke of 'having treats', which largely comprise foodstuffs such as cakes that they believe are contraindicated. Their view appears to be that occasional deviation is not harmful and certainly considered not as risk-laden as consuming alcohol.

Several studies of a range of chronic illnesses have identified nutrition and dietary adjustments as a common factor in lifestyle modification (Whittemore et al., 2002; Lowton and Gabe, 2003; Thorne et al., 2003; Thorne et al., 2004; Rogers et al., 2005; Nagelkerk et al., 2006; Penckofer et al., 2007; Yu et al., 2008). However, its conceived level of importance in respect of medical illness management varies. For example, in those with diabetes, diet is a focal point in the management of the condition and immediate or long-term implications of adherence/non-adherence are greater than for a condition such as multiple sclerosis. However, the importance of adherence to a low fat diet in chronic pancreatitis is not as clear because it does not guarantee amelioration or prevention of pain and gastrointestinal disturbances nor is it

implicated in the progression of the disease (St Kahl et al., 2002). Furthermore, foodstuffs that aggravate symptoms are not limited to those with a high fat content. Thus, while a low fat diet is an adjunct to pancreatic enzyme replacement therapy in the presence of maldigestion and malabsorption, in itself it is unlikely to prevent their onset. As a result, dietary management in chronic pancreatitis has not received notable attention in the chronic pancreatitis literature and does not appear as a medical priority in its management. This finding was similar to that of Rogers et al's (2005) who, following a randomised controlled trial of a self-management programme, undertook a qualitative study with 11 consultants and 28 patients with inflammatory bowel disease. The findings indicated that consultants and patients did not engage in discussion about dietary regimes.

Therefore, although many of the participants' initiation of dietary adjustments are located in professional advice, their ongoing practices are a reflection of the importance of lay beliefs and experience in self-care decision-making (Rogers et al., 2005). This is reflected in much of the self-care literature where departure from medical and professional instruction is common and justified in the context of the individual's lifestyle and the emerging knowledge of their bodily responses (Bennett et al., 2000; Paterson et al., 2001; Whitemore et al., 2002; Thorne et al., 2002b; Thorne et al., 2003; Kralik et al., 2004). Yet, for one participant in this study the lack of professional guidance and support demonstrated the potential risks of relying on experience alone.

6.3.2.3 Prioritising demands

As indicated in the previous chapter, participants experience compromised social role functioning as a result of the physiological disruption of chronic pancreatitis. Whilst the subsequent changes and prioritisation are largely enforced, a small number of the participants took the opportunity to evaluate the competing demands in their lives and make modifications they believed would be beneficial to their welfare. For these participants, exercising some control over factors that were additional stressors in their lives was important.

it wasn't the most important venture for me musically...it was just a job earning money as a musician so I've just kind of stopped all that kind of stuff (Participant 4 – Interview 1)

One participant felt his job was a particular stressor that was implicated in his continued physiological assaults and he successfully applied for another position, which he believed would maximise his skills but eliminate the managerial responsibilities he found particularly taxing.

from the moment I made the decision...literally the stress just started to... the relief (Participant 3 – Interview 3)

Another felt her general life decisions were important factors in enabling her to take control of her life.

I've actually taken a lot of action that needed to be... like moving out of home, changing a lot of things that I was doing...there's more to it than just the pancreatitis. It's a whole kind of life structure, life thing (Participant 11 – Interview 1)

Although these participants had not evaluated the impact of these changes since they were being implemented at the time of the study, their enactment had engendered an overall positive feeling.

The actions of these participants can be likened to those in Kralik et al's (2004) study, where prioritising was one of the strategies adopted to create order from the disorder imposed by illness. By taking action the participants in this study not only recognised and managed the need for change but did so in such a way that they retained control over it.

6.3.2.4 'Struggling to live well'

Although many of the participants, through problem-focussed strategies have made successful modifications to their lifestyle, they also spoke of individual struggles to live well, some of which have been alluded to above, particularly in respect of alcohol abstention. In addition, however, there are universal

struggles experienced by most participants that are peculiar to chronic pancreatitis. These centre largely on balancing the competing demands of work and family commitments with the need to accommodate the burden of arbitrary symptom intrusion associated with the condition.

Primarily, recovering from and coping with physical debilitation associated with salient physiological disruption, hospitalisation and treatment regimes is a struggle for all participants and represents the most significant threat to their efforts to live well. Whatever improvements they achieve in terms of their physical well-being are eroded each time they are hospitalised.

the more I go into hospital the less I'm able to do when I come home, (Participant 3 – Interview 3)

Efforts to regain or sustain physical well-being continue to focus on eating healthily and abstaining from alcohol but at times these efforts are rendered ineffective by the intrusiveness of symptoms.

I thought I'd put the weight back on – I thought I'd be built back up – there's nothing and I tried and tried to eat (Participant 2 – Interview 1)

Maintaining nutritional status and in those with diabetes, achieving good glycaemic control, becomes a secondary concern during times of physiological disruption.

food just isn't an issue...you just want to deal with the pain and that's all you care about (Participant 1 – Interview 3)

Another feels his efforts to eat well are influenced by what he considers are the demands placed upon him in the home.

you see I collect (son), then I have to drop (wife) to work at 2, on my break 2-6 or 2 to half six. So then I collect (daughter) at half-two, do her homework, make the dinner, get the kids the dinner, have my own dinner, get them ready then to go out and play, wash

up after the dinner, collect (wife) from work, bring her home at half six, go back to work, so it's constantly going, going, going. Then all of a sudden at the end of the night when I sit down, realise...what did I have to eat today? (Participant 12 – Interview 2)

In the same vein, many of the participants and their families spoke of the difficulties of balancing their busy lives with the need to combat fatigue and obtain the requisite rest and sleep.

I work now as well so he's not getting much sleep anymore – like he's coming in late last night and he had to be up early this morning because I was in work at half nine (Family member – Wife)

The uncertain illness trajectory of chronic pancreatitis also complicates decision-making, typified by one participant who spoke of his struggle to make decisions that would meet his immediate need to attend to his illness whilst simultaneously preserving his options for the future.

the decision whether or not to carry on a year of college or whether or not to carry on in a band, whether or not to carry on teaching, I mean there's about five or six different things that I've had to decide...do I carry on or do I tell them that I can't do it anymore? (Participant 4 – Interview 1)

Several studies highlight how the task of modifying lifestyle to accommodate the demands of chronic illness is more difficult than anticipated (Lowton and Gabe, 2003; Thorne et al., 2003; Condon and McCarthy, 2006; Nagelkerk et al., 2006; Penckofer et al., 2007). Whilst the emphasis varies depending on the chronic illness, many individuals are overwhelmed, particularly in the early stages, by the demands of attending to the illness whilst maintaining other aspects of life such as work and home. At times then, individuals make decisions to ignore or violate recommended courses of action in order to make room for a valued activity or as a means of 'taking a break' as a method of coping with the impositions and constraints of the condition (Thorne et al., 2003; Penckofer et al., 2007).

6.3.3 Self-monitoring

Throughout their interviews participants and their family members made innumerable references to the processes by which they judge their body's response to their illness. These processes, categorised here as self-monitoring, form a significant part of the participants' everyday self-care undertaken through body listening/observing and recording/measuring – 'I suppose I'm paying attention to it (body) from morning till night – it's all I can do' (Participant 7 – Interview 3).

Not surprisingly, given its nature and prevalence, participants pay most attention to monitoring pain patterns. General trends over time are noted by chronicling the number of acute episodes. Participants tend to use this as an indicator of the progression of the disease.

my frequency of acute attacks has been dropping since '99 – I was probably, at the beginning getting acute attacks maybe every six months or so and now I haven't had one in over a year...the nature of it has changed...it's been a year now since I was hospitalised which for me is a kind of minor achievement (Participant 1 – Interview 1)

Participants also monitor closely their everyday pain, beginning each day by making an initial assessment.

the pain would just be there, and if I take an MST and it doesn't go away, I know it's going to be one of those days (Participant 6 – Interview 1)

Family members also monitor the participants' pain behaviours – 'then you had yourself over that chair – tummy – getting the relief' (Family member – Wife) and use them as a basis for advising on further action.

All participants claim to 'know' by the nature of the pain they are experiencing at any given time whether they can manage it independently or whether it will escalate and require medical intervention.

and no one knows better than myself – I know when it's going to hit me bad (Participant 5 – Interview 2)

Participants said they could not always explicate why they knew the pain would escalate and even though ineffective pain relief and the presence of gastrointestinal symptoms are tangible indicators, it is often the particular configuration of symptoms that prompts concern.

if I spotted that coming, my stool changing I'd say I was in for a belt again (Participant 8 – Interview 1)

I said to (wife), 'I have an awful funny feeling the pancreas is going to flare again' and she said, 'are you sure?' I said, 'I don't know but it's niggling...a dull ache' (Participant 14 – Interview 1)

As a matter of course then, participants observe for overt signs such as abdominal 'bloating' and a change in the frequency, colour or consistency of faeces. Weight is monitored carefully and although it is not a specific indicator of the onset of an acute event, it is considered important in terms of overall nutritional status and/or disease progression. Those who had experienced jaundice also watch for yellow pigmentation in their skin or eyes and/or alteration of urine colour. Changes in sleep quality also form part of their assessment. Bodily sensations such as nausea or discomfort are considered significant as are deteriorating energy levels.

I think I was bloating, because I was finding it awkward when I was walking down the town and I'd feel my legs were tight in my jeans so I felt I was uncomfortable (Participant 2 – Interview 1)

the fatty stool is still showing its face every now and then (Participant 9 – Interview 1)

but in the last six months or so I'd start either getting cold shivers or hot flushes and today I had hot flushes (Participant 10 – Interview 1)

As stated previously, for three of the participants with diabetes, blood glucose monitoring is part of the routine management – ‘I test it every day – three times maybe’ (Participant 2 – Interview 1). Regardless of medical protocols, each of these participants have developed, through bodily cues and experimentation, a blood glucose level that they believe is acceptable and the glucometer provides physiological feedback of their effectiveness in achieving and maintaining their pre-defined target.

it can be 12 at times, but the average in the morning can be 5...I could keep it to 10 most of the time if I wanted to, but I do try and sneak a bit in...I was an awful lot thinner than I am now and I still am thin but I do try and sneak a little bit in so that I can build myself up (Participant 2 – Interview 1)

I’m watching my blood sugars and basically speaking, even when I’m being absolutely angelic they are still high. They’re not mad high, like 8, 10 but not high enough to be really freaking out (Participant 7 – Interview 2)

While the majority of the participants did not record their self-monitoring in a written form, the three who did declared they found it a useful resource for evaluating day-to-day occurrences.

a little notebook that I was trying to keep track of all of the things I was taking, you know food I was eating, drugs I was taking and whatever (Participant 7 – Interview 1)

in it I have what happens to me, day to day – and then the bottom of it I have bowels. And any observations about my body or if anything is flaring up I note that down. And I have another diary, every day I tick off the food I’ve eaten (Participant 9 – Interview 1)

These participants also find that written information is a useful aide memoir in healthcare consultations as it enables them to provide objective data and answer questions that are posed about symptoms.

It's just something you end up regularly doing so that when the doctor asks you the relevant questions you can say well, it has been that or it's not too good this time around (Participant 9 – Interview 1)

In addition, most participants note usage and effectiveness of analgesia as a means of evaluating pain levels over time.

I did have a lot of pain in October because I went through the month's supply of pain killers before I could renew the prescription again (Participant 10 – Interview 3)

Although recording pain levels is not a common practice or routine, when questioned in their interviews all participants readily scored their pain on a numerical rating scale of 0-10, with everyday pain being rated as between 3-4 and acute pain between 9-10.

Continuous appraisal and re-appraisal of their body responses facilitates the accrual of a repertoire of experiential knowledge of their physical selves. Over time, participants came to know the meaning and significance of these bodily cues in respect of disease progression and the effects of treatment, particularly medication. With exposure and experience, they can discriminate between those cues that must be tolerated as part of the illness, those that may be ameliorated by further fine-tuning of their lifestyle and those that require professional help or intervention.

Most have developed a series of self-determined interventions, which when they fail to ameliorate symptoms prompt help-seeking.

I take two of them and if it doesn't go I take two more and if it doesn't go I'm for hospital (Participant 2 – Interview 1)

That's how I know it's getting acute: when I keep doing everything I normally do, and it's not going away (Participant 4 – Interview 2)

However, an important point is that most participants highlighted that they will delay help-seeking as long as possible. Factors cited as influencing this decision are based primarily on past experiences and include an intense dislike of being hospitalised, making certain that the pain will not resolve spontaneously, beliefs that hospital treatment may be ineffective and the anticipated disruption to their social and occupational lives.

it was a Friday morning – I just woke up in agony...it happens every couple of months that it'll get too much with all the medication I'm taking...I held out until I think it was about Wednesday morning 4 or 5 o'clock before I went out to the hospital. I literally have to be on my knees now before I go out to the hospital because of the way it is out there...and I was out there a day and a half before I saw a doctor – obviously a doctor checks in when you're out there but I don't know because I've been out there so much or what it is – a day and a half before I saw anyone and I was in absolute – I think it was the full day, full day and a half of the pain (Participant 5 – Interview 2)

If I went back to him and told him (GP), about the pain that he'd say 'right, a hospital visit'...that's his way of doing things...if I tell him he'll always suggest hospital (Participant 10 – Interview 2)

Conversely, one participant considered, on the basis of his experiences, that it was important to seek help immediately.

if you catch it early...it's very important...before it was last minute before I'd go in...I'd be rolling on the floor – catch it very early now... get bloods taken straight away (Participant 8 – Interview 1)

These findings are consistent with those of several qualitative studies that have reported 'body listening' as an important part of self-management in chronic illness in that it informs cognition and subsequent action (Paterson et al., 2001; Thorne et al., 2002b; Whitemore et al., 2002; Thorne et al., 2003; Rogers et al., 2005). When the body loses its silence in illness, it is inevitable that the person will monitor their symptom experience in order to appraise

and discern the threat or harm to self (Dodd et al., 2001; Wilde and Garvin, 2007). In chronic illness, constant exposure to symptoms and the body's response to them and subsequent treatment or management regimes result in a rich experiential self-knowing. It is not surprising then that people with chronic illness come to rely on their own experience or believe their own body is the best source of knowledge (Thorne and Paterson, 2001; Rogers et al., 2005). They come to know which cues are pertinent and which coping strategies are most effective given the particular pattern of bodily responses at the time (Thorne et al., 2002b). Furthermore, self-understanding is a continuous process and cognitive and behavioural responses to cues adjust and change with time and experience. Thus, living with chronic illness is a constant process that includes being vigilant of body responses (Kralik et al., 2004).

However, those with chronic illness do not rely solely on experiential knowing when self-monitoring. This is consistent with the contemporary view that its attributes include both 'awareness' (bodily awareness) and 'measurements, recordings and/or observations' and is not confined to one or the other (Paterson et al., 2001; Thorne et al., 2002b; Whittemore et al., 2002; Thorne et al., 2003; Rogers et al., 2005; Wilde and Garvin, 2007). Measurements, recordings and observations provide additional appraisal information and facilitate judgement about the validity or otherwise of bodily sensations (Thorne et al., 2002b).

'What' people with chronic illness measure, record or observe is located in the differing nature and character of each chronic illness and the perceived meaning of particular bodily responses or symptom experiences. They tend to judge what is most important in terms of their experiential knowledge but also propositional knowledge of the disease process and symptoms (Wilde and Garvin, 2007). Whilst for the participants in this study, sensory stimuli such as intrusive pain are the most significant, they have also learned that weight and steatorrhoea are notable because they are asked about them in healthcare consultations and in some cases their responses lead to changes in their medical management.

when a doctor asks you at any time about your stool I don't have to say "well, I haven't looked." I can say colour, shape, consistency (Participant 9 – Interview 2)

I took the print outs...and it was then they actually took notice of the weight loss (Family member – Wife)

The implication here is that the medical conception of self-monitoring is narrower than that of the participants' and synonymous with the more traditional definition of recording or measuring associated with disease management (Bennett et al., 2000; Wilde and Garvin, 2007). Thus, participants have learned that objective data as opposed to sensory experience are seen as more legitimate markers of disease and more likely to elicit a response in terms of management or treatment.

To some extent, the absence of objective markers in the presence of pain, offers one of a number of possible explanations for participants' delay in help-seeking. They come to know that there is little they can do to arrest the progression of the condition and experiencing intrusive symptoms is part of its nature. Therefore, in light of their 'knowing' and comparable to that reported by Paterson (2001b), participants begin to 'minimise' or see their symptoms as 'normal' with the result that they tend to delay help-seeking until they are certain it is not so.

it's very hard for, for patients to...they don't know whether they're serious enough to admit themselves (Participant 4 – Interview 2)

'Minimisation' and 'uncertainty' were also findings in Janson and Becker's (1998) study of asthmatics where 86% (n=82) of the sample delayed seeking treatment for severe symptoms.

A further factor proposed by Lefler and Bondy (2004) is that learned behaviours of self-management and self-treatment in chronic illness lead to a self-reliance in respect of symptom regulation. This has some resonance with the experiences of the participants in this study where at onset or escalation of symptoms, they commence a continuous cycle of appraisal, reappraisal,

adjustment and readjustment until such a time that they perceive coping has failed. Whilst this process in itself leads to a delay in help-seeking, previous experience of seeking help or its perceived effectiveness compounds it.

Overarching these factors is the context in which self-monitoring and subsequent decisions about help-seeking occur. Several writers in self-management literature have acknowledged that decision-making in chronic illness is grounded in people's personal and social lives (Paterson and Thorne, 2000; Paterson, 2001b; Kralik et al., 2004). Thus, people make decisions on what is of most import to them at any given time. As outlined above, several of the participants in this study explicated their reluctance to seek help because of the social and occupational disruption being hospitalised entails. They are willing to compromise their physical well-being in order to maintain and sustain the social order in their lives.

6.3.4 Emotional Coping

Part of participants' adjustment to and management of their illness incorporates the use of what are classified as emotion-focussed coping strategies. Whilst these are presented separately from problem-focussed strategies for the purposes of delineation, in the reality of everyday living they are interrelated with a complex interdependency.

As in the 'coming to know' phase of their illness experience, emotional coping comprises the participants' cognitive efforts aimed at regulating their emotional responses to illness. However, an important distinction in the adjusting/managing phase is the existential difference associated with the participants' knowledge that their condition is permanent and unalterable. Thus, the significance and meaning of the illness for their current and future lives changed from pre-diagnosis and appears to be a key mediating factor in how they cope emotionally.

now I have different illnesses so I know I'm not going to get better...and knowing you're not going to get better gives you a different perspective on life as well (Participant 3 – Interview 3)

In the process of adjusting to the reality of living with chronic pancreatitis, it was evident that there are individual differences in the emotional coping strategies used by the participants. It was also apparent from their accounts that these strategies are ever-shifting and dependant on the specific situation or problem being experienced at any given time. This was clearly demonstrated in the data where participants' perspectives changed in a matter of days (diary entries) or between interviews. The example cited below from the same participant reflects a general trend whereby the presence or absence of physiological assault or trauma appears to impact on the participants' emotional outlook.

have I got to live with this all my life? Don't need these feelings
(Participant 13 – Diary Entry)

not to expect to ever feel perfect but thankful in the knowledge that
it is good to be alive and better to be 80% well than not to exist at
all (Participant 13 – Diary Entry)

6.2.4.1 Adjusting expectations

Despite the individual differences in the emotion-focussed strategies used, all participants spoke of having mentally to adjust their expectations.

I've had to kind of adjust around it and I mean you have to...you
lower expectations in a lot of areas – that's one of the key things
(Participant 1 – Interview 3)

However, a critical factor in the acceptability of these adjustments appears to depend on whether or not they can sustain valued activities.

to me I've just plodded on with what I would consider between a
65% to 85% quality of life at varying times and if I could keep it
and have something to look forward to and just live that way I was
happy to do that. I didn't need a 100% (Participant 7 – Interview 1)

For those who believe they cannot maintain an acceptable level of functioning, due to physical decrement and losses associated with the condition, having to lower their expectations appears to impact negatively on their outlook

basically, I think this could be it...this could be just the way things are going to be for good even after all the procedures – after everything is done...that's just a negative way of thinking (Participant 5 – Interview 2)

For this man, this appears to be a protective strategy in the event that planned treatments would not be successful. He seemed, at the time of this interview, to be afraid to hope that his situation would improve and by anticipating that it would not was protecting himself from further emotional and mental distress.

Dispensing with activities that are not priorities or those they are no longer able to undertake enables accommodation of the illness thereby reducing feelings of being overwhelmed. This strategy also appears to offer a level of protection against being confronted with the losses associated with the condition.

start to look positively and say well 'OK – I can do that, that and that – I'll stick to doing that, that and that' and 'I'll discard what I can't do and I'll try and get this on track' (Participant 3 – Interview 1)

For the participants in this study, taking one day at a time is a commonly used strategy in the face of noxious symptoms. From an emotional perspective this enables them to moderate distress associated with bearing the symptoms and is also considered a useful strategy for silencing emotional responses associated with the long-term implications of living with chronic pancreatitis.

I mean I'm OK, getting on with it from day to day...I can tell that I'm better emotionally as regards the illness because I'm coping better during the day (Participant 7 – Interview 3)

For one participant it enabled him to begin to appreciate that he had to concentrate on his 'now' in the face of his dismal prognosis.

does it matter if you die at 47 or 57 if you're not planning what you're going to do right now. It's about enjoying yourself right now (Participant 4 – Interview 2).

Accepting limitations seems to be an important step in adjusting to living with the illness. Several participants spoke about 'having to put up with it' or 'getting on' with their lives. This seems to be about assimilating the vagaries of the illness whilst trying to make the most of what they now had.

I know I'll never be right but if this is the best I'm going to get I'm grateful for it...that I'm able to get out now and do more than I have been doing (Participant 6 – Interview 3)

However, this seemingly more positive outlook is often shattered in the face of setbacks associated with any deterioration in their condition or the onset of an acute episode.

being in pain every day was very tedious and that was emotionally draining...when you're actually in the pain... you are quite happy when you're not (Participant 4 – Interview 3)

Those who struggled with acceptance were experiencing persistent and intrusive symptoms and it is not altogether surprising that they had not 'come to terms' with their changed living. During these times, participants spoke of having to 'endure' in the hope that their situation will improve.

just take it one day at a time, every time I say something I seem to hit a brick wall anyway...something happens, I'm throwing up blood or I'm in bits again or I'm in agony so the way it is now I'm just not going to say nothing until I'm out of here (Participant 5 – Interview 3)

Others, who had achieved some physiological stability and had experienced periods when their symptoms, although present, were bearable, more readily voiced a willingness to accept the everyday uncertainty of living with chronic pancreatitis.

I'm going to have my good days, and I'll take them, I'm going to have my bad days and I will accept them. I'll take the good with the bad (Participant 6 – Interview 1)

This acceptance was located primarily in their good days, which engendered optimism that a future alternative normal was possible. Although the everyday demands of chronic pancreatitis cannot be ignored, during times of perceived wellness or at least in the absence of noxious symptoms it can be relegated to the background.

you just want to make the most of feeling good...I try not to waste time...when I feel good I just want to do something nice because I might just be sitting in front of the telly for the next couple of days if I feel particularly bad (Participant 4 – Interview 2)

Though their acceptance was essentially one of resignation and stoicism located in the perception that they did not have a choice there was an indication that some had begun to identify positive effects of the enforced change wrought by the onset of chronic pancreatitis.

there is an actual upside to that though because I probably would have been dead from drinking had it not have happened (Participant 3 – Interview 3)

I think it's a good experience that happened to me...I always use it as a positive and really the whole illness, both acute attacks and this chronic, every time it happens it makes me refine my life in some way (Participant 4 – Interview 2)

Of these participants, a small number had begun to re-evaluate what was important to them in their lives.

whether it's just the pancreatitis or the range of illnesses that I've got, have brought me to the point where I'm starting to look after me for my own sort of comfort and peace of mind (Participant 3 – Interview 3)

I've kind of had a bit of a second chance...the outcome could've been much different two years ago. So that puts a lot of things into perspective. I've become a lot more conscious of family and staying in touch with family (Participant 4 – Interview 3)

The notion of a second chance or being given their life back was also a feature of the dialogue of two other participants who perceived they had survived near death experiences. Ultimately, this provided the stimulus for a positive transformation of their perspective on life.

I was given back my life and there's no other way of saying it. I've seen three Christmases that I wasn't going to see...and that's probably why I feel committed to living as good a life as I can because I didn't get it back for nothing (Participant 9 – Interview 2)

I call it my second life - I've been so close - it's done a lot for me...but now there's a gift - I know there's more - and every hour is important (Participant 13 – Interviews 1 and 2)

6.2.4.2 Maintaining a sense of control

For several of the participants, maintaining a sense of control over their lives provides an emotional boost. Vital to their perception of control is preserving their independence and, where possible, being self-reliant. This involves mentally 'fighting' the illness and not allowing it to consume them.

it's an entity, you don't want to give it the satisfaction of stopping you in your tracks. You always want to be on top of it and someone's going to win, either it's your physical condition is going to win over your mental condition or it's your mental condition

that's always going to prevail over whatever physically happens
(Participant 3 – Interview 3)

Participants describe consciously striving for balance in order to feel in control.

I think I'm sort of moving into that area of balance that I'm not well, but at the same time I'm not totally unwell either, I can still function (Participant 3 – Interview 3)

However, they recognise that at times this is difficult to achieve in the face of the ongoing illness burden or sudden changes in their lives.

I'm bobbing around under the water but I keep coming up for air...I'm just keeping my head up every now and then for air and I mean mentally now when I say that (Participant 7 – Interview 2)

Some of these participants believe their personality characteristics are influential in enabling or constraining their efforts to achieve a sense of control. Two of them consider that their 'addictive personalities' shape their behaviours and to an extent, the coping strategies they adopt.

so it's hard...my behaviour and my way of coping and coping with this illness – that's all directly reflected in my addictive behaviour and my addictive nature (Participant 7 – Interview 1)

Both spoke of needing 'crutches' as reasons for their past addictions in the face of vulnerability stemming from compromised self-esteem and self-confidence. Even though both recovered from their addictions, they believe the underlying reasons for them continue to exist and exert an influence.

Another participant believes his philosophical outlook is a significant factor in enabling him to cope emotionally with his illness.

I'm very philosophical so it's stopped being emotionally that bad for me...someone of a different mental capacity or mental disposition...

I imagine for someone in a different situation it would be very scary
(Participant 4 – Interview 2)

It was apparent from these participants' accounts that they had reflected and come to recognise aspects of 'self', their situation and the context of their illness that facilitated or impeded their emotional coping. Through this heightened self-awareness, they had begun to exercise some control over the choices they made in responding to their illness.

6.2.4.3 Distraction/Avoidance

Several of the participants spoke of how distraction assists in preserving their emotional well-being. Keeping busy through valued activities such as work, hobbies and meeting family commitments were all mentioned as means of maintaining their sense of a normal functioning self or as a way of diverting attention from noxious stimuli, particularly pain, thereby enhancing their tolerance.

I find it's something to do...I would have nothing probably if I hadn't got that (boxing training) (Participant 2 – Interview 2)

it's the only thing that keeps me sane, is backing horses in the day...because without it I'd go off my head (Participant 5 – Interview 2)

when I'm at work I forget everything even when I have a pain – I'll take the tablets and go back to work and it's there but I'm working away and forgetting about it (Participant 10 – Interview 2)

At the same time, holidays and breaks from normal routine provide emotional relief from everyday living with chronic pancreatitis.

as soon as things veer off the normal schedule I don't cope well. I think that's why the holidays give me such a release because I know exactly what's happening all day, every day when I'm there

and there's nothing to be worrying about (Participant 7 – Interview 3)

For one woman, returning to full-time work and activity altered her mental image of herself as being disabled. Shedding the label enabled her to present herself as a healthy person.

even my family were treating me with kid gloves, taking care of me, constantly anxious about me. Whereas when I came off disability it was like we've proclaimed to the world that you are a healthy individual (Participant 9 – Interview 2)

A small number of participants claim they use avoidance as a means of coping with the emotional distress of enduring symptoms or as a way of suppressing thoughts of the potential effects of chronic pancreatitis.

if I'm feeling really physically bad I don't feel like talking about CP at all – it's the last thing I want to do (Participant 1 – Interview 2)

6.2.4.4 Paralleling

Paralleling is the term used to describe the mainly positive comparisons participants make between their own situation and that of others. This strategy appears to be a means of self-motivation and morale boosting when they are experiencing negative emotional responses to the impact of their illness. Comparisons are made in a number of ways. Primarily, they see chronic pancreatitis as less traumatic than other conditions – 'I know it could be worse...I could have cancer' (Participant 6 – Interview 1).

They also evaluate the level of disability experienced by others and draw positive conclusions about their own situation.

she's only 60 – her right leg and her right arm – she's immobilised...after what's happening to me and the way that poor lady is now – you know at least I can get up and go out, walk for miles (Participant 13 – Interview 1)

Participants make comparisons with others with chronic pancreatitis who, in their view, have more severe symptoms or who have been subjected to more debilitating treatment regimes.

relatively speaking I don't have that much to complain about because a lot of CP patients out there who after they eat, they get terrible pain and to be honest I don't find I'm affected that much (Participant 1 – Interview 1)

I'd still be on a particularly low dose (analgesia)...I don't know how it would compare to anybody else's...maybe I should think of it more often – I could be a lot worse than I am (Participant 2 – Interview 1)

6.2.4.5 Hope/Faith

Many of the participants returned repeatedly throughout their interviews to their specific hopes and their conception of faith and spirituality. Essentially, these are about what sustains them through acute exacerbations of their condition or motivates them to continue to strive and remain positive in their outlook. Hopes appear to be primarily concrete in nature whilst faith and spirituality are more ethereal and related to a way of being.

Hopes are both short and long-term and are expressed differently at different times. For example, during times of physiological disruption, be it episodic or continual or in the immediate recovery phases, the participants' focus narrows and they confine their hopes to a desire for improvement or remission. Progress is measured in smaller steps – 'hope I will be OK, perhaps will feel better tomorrow' (Participant 13 – Diary Entry).

...if I had been somewhere else I probably would have died considering what happened so if you don't die this week it'll be an improvement on last week ...and we'll build from there – it's something isn't it? (Participant 5 – Interview 3)

When they feel well or their symptoms are sufficiently controlled their outlook changes and they tentatively expand their hopes and begin to make medium or long-term plans.

I can look forward to the future now...the only thing I can say is that I'm working to get better...it's very hard to explain that I can see a future now...I'm looking forward to Christmas and all
(Participant 6 – Interview 3)

This constant ebb and flow between short and long-term hopes is a reflection of the unpredictable nature of chronic pancreatitis where setbacks seem inevitable. Therefore, participants' hopes are bound by the context of their illness and adjusted expectations. Moreover, adopting realistic hopes appears to be a protective strategy against further setbacks.

I'm getting good days you know pain is minimal – but I've no doubt that'll come back (Participant 3 – Interview 1)

Consequently, only two participants spoke of a potential cure or making a full recovery.

the only thing I can see is possibly eventually they can clone your own pancreatic cells or something like that, clone the pancreas for you (Participant 1 – Interview 3)

Most confine their hopes to achieving a level of wellness that is acceptable to them.

all I'm thinking of is the long run, because I want to get well. I want to get to a point were I'm well (Participant 4 – Interview 2)

For many of the participants, their main source of hope is treatment options proposed by their consultant. Hope is fostered when in the face of unremitting symptoms, which they cannot control, alternative strategies are suggested.

I feel better now because I know the ball is rolling – when I met you in July there was nothing being done and I was pretty much waiting for my next attack to end up in hospital again...so hopefully now...(Participant 5 – Interview 2)

I just hope they do the operation to be honest with you...as the doctor said, give me my life back...I just want to get well again (Participant 6 – Interview 2)

Conversely, interacting with healthcare professionals can also engender feelings of hopelessness provoked by the perception that their options are limited.

the final blow is (consultant name) telling me that he didn't think I'd get past 47 because I have just given up since I was told that so I said 'well OK – make no plans, do nothing' (Participant 3 – Interview 1)

but there was nowhere else to go...I've been to all these people – what are they going to tell me now after seven, eight years that they haven't told me already that's going to change anything? (Participant 7 – Interview 1)

For six of the fourteen participants in this study, faith and spirituality co-exist with hope although none made specific reference to faith as a factor that engendered hope. Instead, faith and spirituality are a source of strength, a means of obtaining emotional and mental comfort and a way of relieving fears about the future regardless of whether they are synonymous with organised religion or whether it is located in a philosophical way of being, such as Buddhism.

I'm sort of very heavily influenced by an awful lot of spirituality...and I suppose now I live my life very much toward Buddhist philosophy (Participant 3 – Interview 3)

going on about the Buddhism...I'm completely unafraid of death
(Participant 4 – Interview 2)

I also feel very comforted after the rosary... I feel the benefits in a
more spiritual way (Participant 13 – Interview 2)

Part of feeling comforted is partaking in practices that are in keeping with
their faith. For some, this includes participating in religious events such as
Mass or prayer whilst others perform meditation. One man identified
performing or listening to music as being spiritual for him.

when there's four musicians and there are people watching in the
room there is an energy that you could only describe as something
very spiritual or something more than emotional energy or physical
energy and it really is tangible (Participant 4 – Interview 3).

For two of the participants, becoming ill and being diagnosed with chronic
pancreatitis has augmented their faith.

in actual fact, it's brought me back to the church and I do feel a lot
more peace of mind... (Participant 13 – Interview 1)

Although the strategies presented herein encompass those most clearly
identifiable from the participants' accounts, they cannot be said to be a
complete or definitive representation given the ever-changing, complex and
individual nature of emotional coping. Nonetheless, there is considerable
support for their existence and use in a wide range of reviews and studies of
coping (Snow-Turek et al., 1996; Mahat, 1997; Dewar and Lee, 2000;
Lansbury, 2000; Burker et al., 2004; Dunn, 2004; Keil, 2004; Blyth et al.,
2005; Lohne and Severinsson, 2004; Dunn, 2005b; Kylvä, 2005; de Gouveia
Santos et al., 2006; Persson and Rydén, 2006; Klein et al., 2007; Lundman
and Jansson, 2007; Pieterse et al., 2007; Haynes and Watt, 2008; Yu et al.,
2008).

However, there are disparate findings in these studies related to both the
classification and perceived effectiveness of some emotion-focussed

strategies. For example, distraction has been determined to be both effective (Dewar and Lee, 2000; Persson and Rydén, 2006; Klein et al., 2007; Haynes and Watt, 2008) and ineffective or maladaptive (Pieterse et al., 2007) and an 'active' (Blyth et al., 2005) or 'palliative' (Pieterse et al., 2007) coping strategy. Praying and hoping have also been classified as active strategies (Blyth et al., 2005; Haynes and Watt, 2008) and therefore beneficial (Dunn, 2005a; Yu et al., 2008) although in the Coping Strategies Questionnaire (CSQ), they are defined as passive (Snow-Turek et al., 1996). As a broad observation there appears to be a tendency in the population-based and cross-sectional or correlational studies to associate the use of some emotion-focussed coping strategies with higher incidence of psychological distress thereby leading to the conclusion that such strategies are ineffective or maladaptive (Snow-Turek et al., 1996; Burker et al., 2004; Blyth et al., 2005; Dunn, 2005b; Pieterse et al., 2007). According to Coyne and Racioppo (2000) evaluation of coping effectiveness in this type of research is focussed too narrowly on the supposed goal of psychological distress reduction and fails to take into account that people approach difficult situations with multiple and possibly alternative goals.

They also argue that some of these contradictory findings are related to the use of over-inclusive, summary categories of coping, such as active versus passive (Coyne and Racioppo, 2000). This is perceptible in studies that examine overall coping styles (Pieterse et al., 2007) where the individual's final classification indicates a general coping disposition that cannot adequately reflect the multiple strategies used in different situations. Furthermore, it seems the ultimate determination of what constitutes active/passive, effective/ineffective coping is related to the researcher's perspective and the choice of instrument for data collection. The use of standardised measurement tools across individuals, in one-off situations fail to acknowledge aspects such as context and timing (Coyne and Racioppo, 2000; Somerfield and McCrae, 2000; Tennen et al., 2000; Persson and Rydén, 2006).

In recent years, however, an argument has been forwarded that a more complete and holistic understanding of the individual nature and complexity of coping can be achieved by using methods such as those undertaken in this

study (Tennen et al., 2000). Studies that have a narrative approach offer some support for the finding in this study that various emotion-focussed strategies co-exist and are used concurrently. The findings of some studies posit that there is 'no special way to be' and flexibility may be more adaptive ultimately (Dewar and Lee, 2000; Persson and Rydén, 2006). Therefore, care must be taken in determining if emotion-focussed strategies are maladaptive since even those that are generally regarded as such, may be beneficial at times (Keil, 2004).

6.3.5 Drawing on social resources

Although much of the responsibility for adjusting to and managing their living with chronic pancreatitis rests with the participants, they all spoke of social resources they draw on in their daily lives. These include family, friends, and professional and state agencies such as the welfare system. Whilst information support, delineated earlier, continues to be an important resource, the focus of the discussion here is on what constitutes emotional and practical support. A noteworthy caveat, however, is that whilst they are valuable in facilitating everyday living, accessing or drawing on these resources can also cause frustration and conflict when they do not meet the participants' expectations.

6.2.5.1 Practical support

As in the pre-diagnostic phase of the participants' illness, family and friends provide continuing practical and emotional support. Practical or tangible support spans a wide range of actions that are determined, to a large extent, by the degree of debilitation being experienced at any given time. Examples include the provision of convalescence, transport to and from hospital or other appointments, facilitating dietary adjustments, ensuring prescription medications are filled and assisting with the completion of household or other commitments.

he (father) came with me last Thursday – fair play to him cause everywhere I went it was for an hour – an hour in one place, an hour in another and an hour in another – just three hours of just sitting down waiting (Participant 5 – Interview 2)

when I came home, I stayed with my youngest sister for my recuperation period (Participant 9 – Interview 1)

I didn't stay in this house at all, I was in my nephew's house...I had to stay there for six weeks – 'cause this (his home) was cold and damp and they looked after me very well (Participant 13 – Interview 1)

For some participants, neighbours and friends are also an important source of tangible support.

they went through the list of hospitals with me and then he was trying to arrange who would give me a lift to the hospital...so they are very, very supportive (Participant 4 – Interview 1)

I had to ring the old man across the road there – there was two electricity bills and a warning – I told him to pay them and I would pay him when I came back (Participant 13 – Interview 1)

Apart from family and friends, some participants spoke of the practical support they receive/d from social workers and/or the social welfare system.

they were very understanding. They helped you fill out the forms and they would go through it with him (Family member – Wife)

she said, 'sure are you not entitled to disability benefit?' I said I was told I wasn't because I didn't have enough stamps. She said 'did you ever work in another EU country?' (Participant 9 – Interview 1)

However, a number of the participants outlined how they find negotiating the social welfare system confusing and tangible help is not always available.

they're not helping me anyway I know that. I thought they were there to help you and advise you what to do. No, I just find they make things awkward for you (Participant 8 – Interview 3)

I was meant to get the social welfare thing and all to sort out the payments in the hospital and your one said she's help me do this and help me do that but she never did (Participant 12 – Interview 1)

Although most participants had not sourced additional help in these situations, they identified services like the Citizens' Information Centres as a potential resource.

I think I'll go into Citizen's Advice crowd and ask them what to do and sort me out, although I'm saying that for the last few months and I didn't go in to see them yet. (Participant 8 – Interview 3)

Two participants identified their General Practitioner as being a useful practical resource in securing and sustaining social welfare entitlements.

if she puts the pancreatitis down as the cause of the diabetes, not the other way around that she can justify the painkillers (Participant 3 – Interview 3)

in the middle of all that too-ing and fro-ing I lost my medical card...with the 20 hours and my disability I was earning too much...so my doctor had to fight with me to get it back... it took another two months before I got my medical card back (Participant 9 – Interview 2)

6.2.5.2 Emotional support

Despite changes in personal relationships as a result of illness, family and friends are a vital source of emotional support. Much of this is in the form of actions that convey concern for the participants' well-being.

we're both very much in tune with how each other would be sort of feeling about something. She'll know when something's wrong, so she'll start hanging around... (Participant 3 – Interview 2)

she's very good...she comes down for an hour or two in the morning...make sure I'm alright, then she'd text me, or ring me...(Participant 6 – Interview 2)

he had to have some kind of company and he didn't want to moan in front of my parents. So I'd just go up and spend hours in his room and talk to him about it... (Family member – Sister).

Although none of the participants made direct reference to feeling cared for or loved, it was inferred that when family or friends express 'worry', it is indicative of their caring.

I actually cried when I was there at the party...I really did. I cried because it was sad (Family member – Wife)

I knew by her that she was actually more down than I was...she wasn't crying or anything but she was very, very close – to nearly breaking down there (Participant 14 – Interview 3)

Some participants also reported how they feel emotionally supported by others such as work colleagues when they are considerate in facilitating the necessary adjustments to their lives.

I was out last night with the staff...I had a great night...I said at the end, 'I'll bring you for a drink.' And they said "No, we deliberately said half five, so you wouldn't drink." And that's great, to have the girls and the fellas look after me like that...I thought that was powerful (Participant 3 – Interview 3)

he says, 'now it's hard for you working here...if you want I'll let you go even before we're finished cleaning...before everyone starts to sit down and have their pint' (Participant 12 – Interview 3)

One participant spoke of how an act of kindness from strangers was emotionally uplifting.

'she has no cancer'...and they all just cheered, and I thought it was the loveliest thing, all these people watching their relations that, you know, were terminally ill and they stopped to cheer for me (Participant 9 – Interview 1)

One participant stated that although her family offer as much practical support as she requires, she had not discussed her emotional needs with them even though she said she would like to. She attributes her husband's reluctance to engage emotionally to the fact that he is not 'that type of person' but also that he had difficulty accepting her illness – 'I think he was hoping that I could get better' (Participant 6 – Interview 3). She also expressed a reluctance to burden her children with her emotional needs as 'they have been through enough' (Participant 6 – Interview 1). However, protecting others, which is also a feature of other participants' accounts appears to create additional strain associated with trying to contain one's emotions.

I'd love to scream, you know?...it's very hard to cope with (Participant 6 – Interview 1).

Moreover, participants have expectations of receiving emotional support and when it is not forthcoming they feel hurt and devalued.

you have not really spoken about having chronic pancreatitis with anyone. You wouldn't tell your friends particularly as you felt they did not really care or were not really interested (Participant 5 – Interview 1 researcher's notes)

I'm having such issues with my mother that I think in some way I do blame her...my mother will not believe now even that I have a problem, which is not good for me (Participant 7 – Interview 1)

One family member offered that these responses are indicative of others' inability to cope – 'I just reckon he (friend) couldn't deal with him himself so he just ran away' (Family member – Sister). Whatever the underlying reason, participants tend to distance themselves or withdraw from these relationships in order to protect themselves from further emotional pain.

A small number of participants obtained emotional support from professional counselling services that were recommended by healthcare professionals or that they accessed independently. Although only one participant was attending counselling at the time of the study, others outlined how they had found them useful in the past.

I went to a counsellor myself before Christmas for 10 weeks...and I found him very good (Participant 7 – Interview 1)

when I go to meetings (Alcoholics Anonymous) I don't think that I'm going to them because I'm an alcoholic. I'm thinking of them as part and parcel of my daily kind of routine or keeping well (Participant 11 – Interview 1).

However, one man who said he had found attending Alcoholics Anonymous helpful stated the timing of the meetings precluded his attendance once he returned to work. Furthermore, he declared he does not have the financial resources to pay for private counselling – 'you know paying 60/50 euro for one session for an hour' (Participant 12 – Interview 2). This man's wife stated she had requested psychological support from the hospital but it had not materialised.

the doctor said 'yeah we would', and they never did...so once he was let out of the hospital it was a case of 'off you go, look after yourself and we hope we don't see you here again' (Family member – Wife)

Yet another found attending Alcoholics Anonymous ineffective.

listening to the same stories every night, fellas that had lost their houses and their farms and their wives and children – it would drive you to drink. The AA didn't work for me I know that (Participant 8 – Interview 2).

It appears from these findings that participants' practical and emotional resources are rooted primarily in their social network yet limited to those with whom they feel they have a significant bond. Adjusting and managing incorporates retaining and sustaining these relationships while simultaneously relinquishing those that have been found wanting in the face of illness. Relationships with outside agencies such as social welfare can facilitate information and practical support and are therefore necessary for negotiating the welfare state but are essentially devoid of any sense of being an emotional support. Furthermore, when anticipated support from these agencies is not forthcoming it is a source of frustration. In addition, whilst healthcare professionals are considered an important source of information and in some cases practical support, none of the participants made reference to them as a source of emotional support. Emotional support is the domain of family and friends although professional help has been sought by some who have recognised that their needs go beyond their available resources.

A number of studies and reviews have been undertaken that offer support for these findings. According to Hinson Langford (1997), emotional and practical (instrumental/tangible) support are two of the key characteristics of the concept of social support. Social support has been identified as being pivotal in enabling people to cope with and adapt to the demands of illness (Fridfinnsdottir, 1997; Hinson Langford et al., 1997; Hagerty and Williams, 1999; Hansson and Ahlström, 1999; Dewar and Lee, 2000; Kyngäs et al., 2001; Choenarom et al., 2005; Cunningham and Jillings, 2006; King et al., 2006; Persson and Rydén, 2006; Haynes and Watt, 2008; Yu et al., 2008). The majority of this literature associates social support with a reduction in negative emotions, although the relationship appears to be an indirect one with social support having either a stress-buffering or stress-mobilising effect (Hagerty and Williams, 1999; Choenarom et al., 2005; Pieterse et al., 2007).

How social support buffers or mobilises coping resources is less clear but it has been suggested that it enables people to handle things (Kyngäs et al., 2001), it may improve self-care (Yu et al., 2008), foster resilience (King et al., 2003; King et al., 2006), encourage and assist with illness induced modifications to lifestyle (Nagelkerk et al., 2006) give relief and solace from knowing that others care and can be relied upon (Lundman and Jansson, 2007) and contribute to a stronger self-efficacy (Monsivais, 2005).

6.3.6 Interacting with the healthcare system

For the participants in this study, part of adjusting to living with chronic pancreatitis is the accommodation of regular interaction with the healthcare system for the purpose of being monitored and being treated. Encounters with the system and those who work within it are primarily hospital-based and range from minimal contact associated with prescription renewal and outpatients appointments to the more intense phases of contact associated with hospitalisation. Apart from their general practitioner, participants have no contact with any other community-based service, although some seek advice from their local pharmacist. Some general practitioners facilitate alterations to pharmaceutical regimes but most confine their involvement to implementing the prescribed hospital therapy and acting as a conduit for access to hospital-based services.

How the participants adjust and cope with incorporating interaction with the healthcare service is predicated on a number of interpersonal, intrapersonal and infrastructure factors. By far the most cited factor is their perception of healthcare professionals' responses and attitude to their illness.

CP is almost like the dirty secret of a condition that...you know the medical profession see it as a kind of self-inflicted problem that winos in the street get...I have been kind of shocked by some of the attitudes I've come across with CP (Participant 1 – Interview 3)

I had it down that I drank the 14 pints a week at the time...didn't hide it...I was honest...when I read it – I said 'Holy Jesus' and my wife said the same...say for instance now you did not know me and

we hadn't spoken and someone handed you these (doctors' letters)
– you'd say I was a raving alcoholic (Participant 14 – Interview 2)

As described in the previous chapter, these responses engender feelings of anger and frustration, which in turn lead to a sense of being stigmatised and discredited.

you are not to be trusted with opiates...somehow the implication is you're an addictive personality and you're only in here to get your paws on opiates – that's your whole rationale for arriving in casualty (Participant 1 – Interview 2)

I've only ever seen (doctor) once for 5 minutes, called me into his office told me he had spent 4 and a half hours reading my charts, told me I was f***ed and let me go (Participant 3 – Interview 1)

doctors, they reinforce that 'it's your fault' you know? So what I'm getting to now is saying 'f*** them I won't even go near them – I'll stay away from them'. If I stay away from them, that way I don't feel I'm being told 'nah, sure what do you expect?' (Participant 3 – Interview 1)

As a result of these perceptions and experiences, participants tend to limit their interaction to the minimum necessary to maintain contact with the system that is part of their ongoing care. Thus, most participants attend their regular outpatient consultations although they often feel they are of little value in enabling their day-to-day living with chronic pancreatitis. This is because consultations are confined largely to medical treatment and being directed to comply with medical instructions. Furthermore, it is evident from the participants' accounts that they found it difficult to challenge treatment regimes on the basis of their experiential knowledge.

western medicine...when it doesn't look at the whole individual – it doesn't look at the whole body and it's so cold in its representation...really it's kind of car mechanics you know – it's human mechanics and for me it's entirely objective and you are

sitting there as a very subjective individual. I mean all you know is what you experience, and you are sitting there on the other side of it. (Participant 4 – Interview 3)

we need to be a little more forceful when we go in...he has that effect on you though cause he's so plamásing and I do recognise that but I do need to tell him that this isn't working and he says I'm so highly strung. He keeps telling me how highly strung I am and I'm expecting everything like now (Participant 7 – Interview 2)

In addition, system processes such as lack of continuity of medical personnel, short consultations and busy clinics prevent discursive interaction.

it makes me angry – I have to get up at five o'clock in the morning and get someone to drive me into town, I go away up and I talk to him for 10 minutes... (Participant 8 – Interview 1)

there was a mile of people in front of me and behind me (Participant 14 – Interview 1)

Even though some participants accept the 'status quo', others have adopted strategies that are perceived as minimising the constraints or enhancing the likelihood of efficacious interactions. These include changing doctors and hospitals, accessing consultations through the private sector, confining consultations to a trusted general practitioner, not attending all outpatient consultations and telephoning in advance of appointments to ensure they are scheduled to meet with the consultant rather than other members of the team.

Similarly when seeking healthcare during acute episodes, participants utilise strategies they have found most effective in either limiting the 'waiting' time or increasing the probability of 'getting a bed'.

if there's no public room...a private room may come up so that by continuing to pay the VHI, I increase my chances of being admitted rather than be messing around (Participant 1 – Interview 1)

usually they're fairly good now, I get a bed, my GP at the centre, he's my own doctor...anyone that gets a letter, he must have terrible pull in there or something, or else they're afraid of him (laughter) (Participant 8 – Interview 1)

I went in there on Friday morning – about half four in the morning – now there's a reason for doing that – there's no big queue in casualty at that hour of the morning – I learned that years ago – you've more chance of getting a bed on Friday than any other day of the week (Participant 14 – Interview 1)

Although not always possible for those who are geographically removed from their treating hospital, most participants take steps to ensure they are taken to the 'right' hospital.

to save me staying in casualty all night (husband) got the doctor...so he stayed here and made sure that the ambulance brought me to (hospital name)...he contacted the casualty (Participant 6 – Interview 3)

Despite their efforts, participants recounted numerous episodes of enduring long waits for initial treatment and access to hospital beds.

for three days...there was nothing wrong with it – I didn't find anything wrong with it being on the trolley...it's not their problem...it's the doctor – getting a doctor to you (Participant 2 - Interview 1)

it's going through casualty and like sitting there for seven or eight hours...now. I don't expect special treatment...but being left in the corridor... (Participant 6 – Interview 1)

I tell you it's terrible though, you can't shower or anything properly, you know, in the A&E...very degrading (Participant 6 – Interview 3)

Although most declared satisfaction with care once hospitalised, several of the participants report how they make every effort to expedite their discharge. This largely involves rigid compliance with treatment regimes but for some includes non-disclosure or minimisation of symptoms.

within a couple of hours just being over at the square walking around he was in agony again and he never told the doctors (Family member – Wife)

'how are you feeling?' 'Grand – I feel a lot better now', I said. 'Well' he says, 'there's still a bit of inflammation there...we're planning on keeping you...' 'oh no', I said, 'I'm grand, I want to go – I feel great'. He says, 'no more pains?' I knew it was killing me but I thought 'f*** it I'm going'...I still had the pain for a few days after that but I just wanted to get out of bloody hospital (Participant 14 – Interview 3)

Although some of these interactions with the healthcare system can be said to be particular to individual participants, there are trends related to the social context in which healthcare is delivered and received and in the illness conception of chronic pancreatitis that influence their appraisal and coping behaviour. In their study of 19 people having elective orthopaedic surgery, Edwards et al (2004) proposed that patients' awareness of the macro and micro social contexts in which healthcare takes place affects their constructions of satisfaction with it. Macro awareness concerns the social, political and financial contexts in which care is received while micro awareness relates to interpersonal relations and maintaining constructive associations with those providing care. Some of their findings regarding patients' cognitive appraisal and reappraisal have some resonance with the findings of this study. Locating ongoing monitoring and treatment primarily within the hospital-based service perpetuates the notion of chronic pancreatitis as a condition requiring specialist management skills. This view is reinforced by the participants' perception that few know about the illness, as evidenced by the reluctance of general practitioners to initiate or alter treatment regimes and/or being labelled an 'alcoholic'. Furthermore, as cited earlier, participants' experiences of what they determined was 'poor', 'inexpert' or

'inappropriate' treatment by other hospitals, or clinicians, propagated their belief that specialist skills are required and that they are 'lucky' to have been referred to their treating consultant.

Moreover, and similar to the findings of other studies (Edwards et al., 2004; Thorne et al., 2004), participants need to maintain their relationships with healthcare professionals and the system in which they work for the purposes of disease monitoring and treatment. Therefore, on an interpersonal or micro level, participants in this study are reluctant to challenge the expertise of the healthcare professional and are largely passive in their interactions. The voice of the healthcare professional dominates and the nature of the communications reflects the expectation that they will comply with medical instruction, a view supported by Stevenson et al (2003). Conformance is questioned when physiological disruption or acute events occur, a finding Paterson et al (2001) describe as arising from the myth that compliance will result in few untoward symptoms or complications in those with chronic illness.

Feeling discredited, stigmatised, delegitimised or dehumanised in some interactions with the healthcare system and the professionals with whom participants consult was also a finding in qualitative studies of dissatisfaction with healthcare (Coyle, 1999) and healthcare communication in chronic illness (Thorne et al., 2004). Being labelled 'highly strung', being told they were 'f***ed' and not being treated as a 'whole' are examples in this study of what Coyle (1999) refers to as interactional rule breaking, where the socially acceptable and taken-for-granted rules governing communication are infringed. Both Coyle (1999) and Thorne et al (2004) refer to how courtesy or lack of it facilitates or impedes the flow of the interaction but more significantly how it affects the patient's overall perception of the model of care, competence of the practitioners and beneficence of the healthcare organisation.

A further dimension is that these complex interpersonal processes occur within the social, political and financial context of healthcare provision. In Ireland, there has been much controversy in recent years surrounding waiting times in Accident and Emergency, prolonged waiting for services by public

patients, staff shortages and ongoing pressure on services. Consequently, the participants not only expect to have to wait for services but when they personally experience inadequate service provision tend to normalise it within the context of the universal problem. Edwards et al (2004) highlighted that the macro context of the UK National Health Service in which their study was undertaken also mediated their participants' behavioural responses because experiencing long waits was common. Similar to some participants in this study, their participants expressed a general reluctance to seem ungrateful or be overly critical.

Furthermore, whilst the development and strengthening of primary care services is an aspiration of the health strategy in Ireland (Department of Health and Children, 2001b; Department of Health and Children, 2004a), there has been a traditional over reliance on acute hospital care (Department of Health and Children, 2001a; Department of Health and Children, 2008). Participants in the current study do not appear to have any expectations regarding the availability of support in the community. This finding was echoed in Condon and McCarthy's (2006) study of Irish patients' lifestyle changes following myocardial infarction where there was no anticipation that primary care services would be of any help following discharge from hospital. Moreover, hospital-based services seem to be regarded primarily as a source of information rather than support. They conclude that this may be explained in part by cultural factors where patients have low expectations of service provision and are grateful for any help that is received.

That the coping strategies of the participants in this study are mediated by the context in which healthcare takes place seems evident. However, given the nature of this study, what is more difficult to determine is if their adopted strategies are effective and/or ineffective. For example, whilst avoiding interaction with the healthcare system could be deemed ineffective in terms of ongoing management of their illness, at the same time it may offer some emotional protection of self from dehumanisation.

Nonetheless, the participants' accounts indicate that there is considerable potential for improving support in the acute and primary care sectors. Furthermore, their experiences suggest that a more integrated service across

the sectors may enhance self-management, a factor considered central to improved health outcomes in chronic illness (Paterson, 2001a; Paterson et al., 2001; Thorne and Paterson, 2001; Meetoo and Temple, 2003; Rogers et al., 2005; Haidet et al., 2006). This has been recognised at policy level in the context of the Primary Care Strategy (Department of Health and Children, 2001a; Department of Health and Children, 2004a) and more recently with the development of a Policy Framework for tackling Chronic Disease (Department of Health and Children, 2008). However, it is recognised in the latter report that, with the exception of cancer, diagnostic registries do not exist in Ireland, clinical guidelines and protocols are generally not available and the current model of healthcare delivery is not well equipped to meet the requirements for effective chronic disease management (Department of Health and Children, 2008). Furthermore, while there is a commitment to active patient participation in their care, a self-care programme for chronic illness remains at the developmental stage and it is not clear whether there is patient involvement in its construction (Department of Health and Children, 2008). Nevertheless, the implementation of the proposed strategies has long-term capability of impacting positively on the lives of those with chronic pancreatitis. In the meantime, however, it is suggested that even within the limits of the current service provision, improved information and support and greater patient participation in decisions about the management of their illness could address some of the issues highlighted by the participants in this study.

6.3.7 Summary

Adjusting/managing is a highly complex and on-going process incorporating an extensive range of problem-focussed and emotion-focussed coping strategies. How these strategies are configured within the context of each person's life essentially constitutes their self-management. Its representation in this study is that it encompasses everyday strategies and routines whilst simultaneously taking cognisance of medical instructions and treatments. Furthermore, it is not static but evolves and changes with time, knowledge and experience and as life and illness circumstances alter. This is consistent with the claim that the lay concept of self-care involves psychosocial and everyday dimensions of health (Stevenson et al., 2003). Traditionally,

however, healthcare professionals have tended to see it as supplementary or even separate to medical care. Many consider this view to be too narrow and they propose that self-care or self-management should incorporate and make reference to patients' experiential self-management strategies (Burks, 1999; Bennett et al., 2000; Paterson and Thorne, 2000; Paterson, 2001a; Paterson et al., 2001; Thorne and Paterson, 2001; Thorne et al., 2002b; Thorne et al., 2004; Paterson et al., 2006). However, similar to the findings of this study, self-care is often framed from a biomedical perspective (Haidet et al., 2006) and patient participation is limited (Paterson, 2001a; Rogers et al., 2005; Paterson et al., 2006). These writers also argue that positive engagement by both healthcare professionals and patients is necessary for effective self-care or self-management.

6.4 Interpretation

For the participants in this study, 'coming to know' and 'adjusting/managing' describe the second meaning of enduring disruption ('to cope with' and/or 'to tolerate'). The complex and multidimensional nature of the themes and sub-themes and the synergistic relationship between them has been demonstrated. In addition, it has been illustrated how the participants are in a continual cycle of coming to know and adjusting/managing (self-management) through everyday living with chronic pancreatitis and as they acquire new knowledge and information.

The representation of enduring disruption as delineated in this chapter, describes the process of transition from 'well person' to a person who lives with chronic pancreatitis (Figure 6.3). According to Kralik et al (2004) transition is about how people respond to change over time. In this study, change was enforced by virtue of being diagnosed with chronic pancreatitis. In coming to know disrupted body and chronic pancreatitis, participants became aware of their permanently altered lives. Subsequently, in 'adjusting/managing', they came to know the nature of these alterations and mobilised coping strategies and resources to modify or minimise the impact on their current living whilst endeavouring to maintain or maximise their health potential for their future. Pivotal to this process is the distinction between awareness of a permanently altered life and knowing it as a result of living it. Through daily living, the participants continually develop their knowledge of their body's response to illness and how best to react to what it is telling them. As a result, they are learning how to live with the limitations of their body, and accommodating the demands of their illness is being embedded into their daily living. Adjusting and managing change through the use of self-management strategies not only indicates immersion in the transition process but is integral to it (Kralik et al., 2004; Kralik et al., 2006) as these strategies essentially describe engagement with the process (Meleis et al., 2000; Kralik et al., 2006).

A further marker of being in transition is awareness of difference (Meleis et al., 2000; Kralik et al., 2006) and is exemplified in this study by participants' accounts of how their physical, psychological and social selves and

consequently, their lives are different. Central to this is recognition and acceptance that a return to their 'old' normal is no longer possible. At the time of the study, most participants appeared to have arrived at this point of realisation although they were still struggling to come to terms emotionally with the change. Even though they accepted that they could not 'go back' to their old life, some identified that a future life as it was during their participation in the study would be difficult to bear. These participants had not yet identified an alternative life construction that was acceptable to them. Illness remains in the foreground of their lives to the extent that their future is suspended.

There is a suggestion in the literature that the process of accepting or coming to terms with illness is dynamic and continuous rather than sequential and marked by alternating periods of balance and imbalance (Paterson et al., 1999; Kralik et al., 2003). One reason is that the demands of the physical illness cannot be ignored or silenced and as Kralik et al (2003) argue, they take precedence over dealing with identity and self. This is reflected in the current study, where uncertain body and an unpredictable illness trajectory mediate the participants' acceptance. Sustaining a positive outlook is difficult in the face of disequilibrium and instability caused by signs of disease progression and/or further losses. All participants appear to experience conflicting emotions that challenge their efforts to accept the difference in their lives. Acceptance wavers when progress is disrupted by setbacks and participants seem to be in a continual phase of re-ordering.

Moreover, acceptance or coming to terms with chronic illness also includes a deeper psychological incorporation of changes that facilitate a reorientation (Kralik et al., 2006) or restructuring of self (Paterson et al., 1999). Coming to terms with being a person with chronic illness involves finding meaning in the experience (Paterson et al., 1999) and redefining self-identity in the face of adversity (Bury, 1982; Charmaz, 1991; Kralik et al., 2006). For the participants in this study, the reality of their situation is acknowledged but emotional acceptance of themselves as a person with chronic illness could not be said to have been achieved. They were still learning about the condition and its impact. They were at a point identified by Godfrey (2008) as an 'uneasy' acceptance. Only a few had begun to find meaning in their

experiences. These findings are supported by others where some aspects of chronic illness were accepted more readily than others (Lee and Poole, 2005; Lundman and Jansson, 2007; Godfrey, 2008).

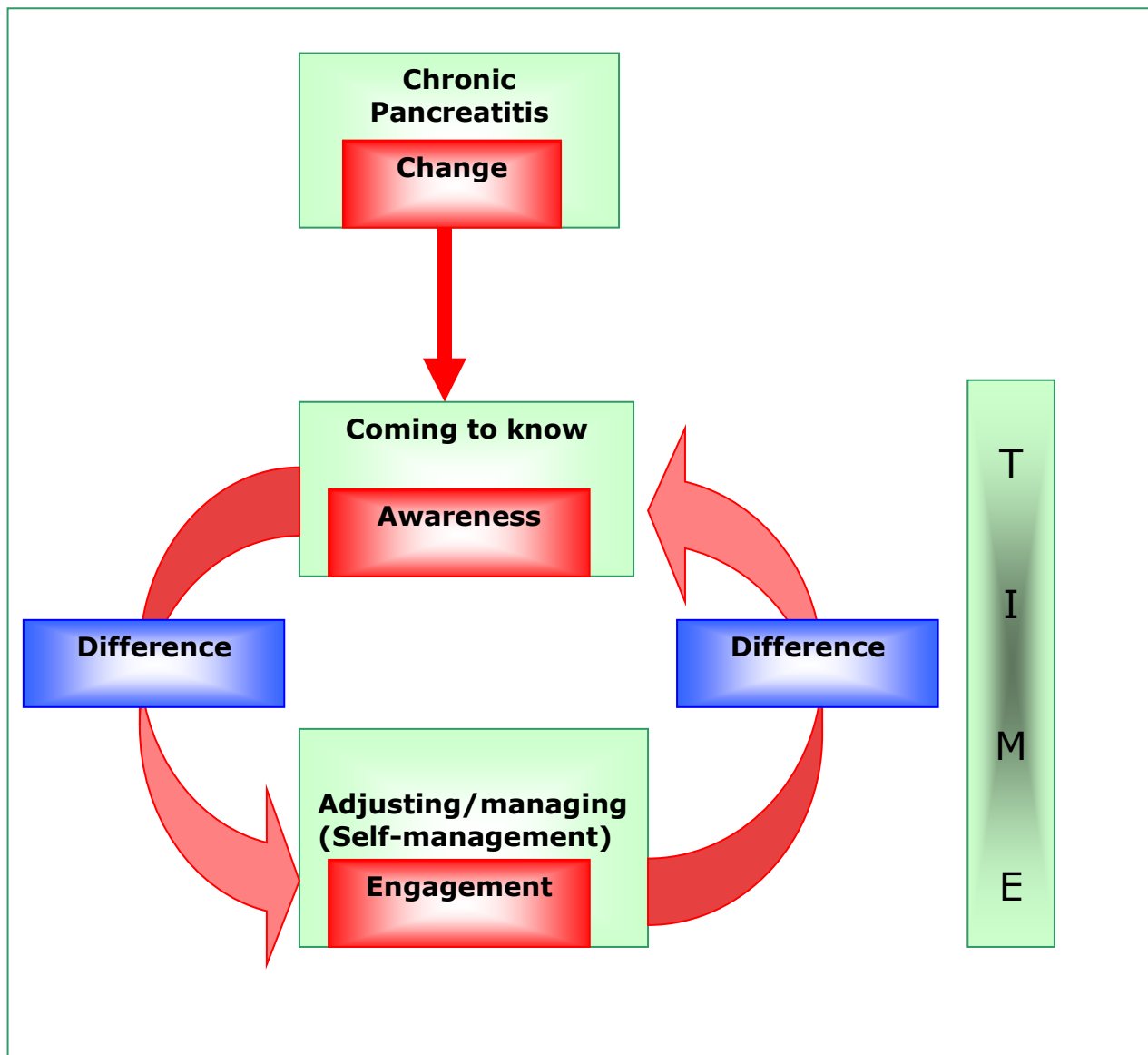
Yet, chronic uncertainty can become the foundation on which the new sense of order is ultimately constructed (Mishel, 1990; Mishel and Clayton, 2003). When uncertainty is accepted as the natural rhythm of life, new possibilities are identified and uncertainty becomes an opportunity rather than a threat (Mishel, 1990; Mishel and Clayton, 2003). However, at the time of this study, none of the participants viewed the pervasive uncertainty, particularly in respect of their future lives, as other than a threat. Disentangling the uncertainties associated with unpredictable body and illness trajectory from those related to their future existence, led me to what Penrod (2007) describes as the distinction between 'situational' and 'existential' uncertainty. Situational uncertainty is where doubt exists in reference to a particular context while existential uncertainty is concerned with the broader issues of human existence. In the current study, it is suggested that situational uncertainty is a feature of the participants' everyday living but existential uncertainty also exists in respect of their future.

In coming to terms with their illness, as many of the participants become more proficient in self-management, there are indications of a sense of being in control and having more confidence in managing situational uncertainties. However, key aspects of acceptance, such as having a positive view of a future life that encompasses hope and optimism (Younger, 1991) are not evident for most. As indicated earlier, their unknown future remains a source of discomfort and distress and few are optimistic about it. It is suggested therefore, that for those with chronic pancreatitis, existential uncertainty may never be resolved fully and the challenge is to learn to live with it. For many, even those who had begun to positively re-evaluate their lives, this appears to be about living in the present and addressing each new challenge as it occurs. Whether this is a protective strategy to enable them to process the assault on their 'self' is unclear but Penrod (2007), in her concept advancement, also found that a present-oriented state of being exists in the presence of uncertainty. Furthermore, she asserts that in some life events uncertainty is a

normative state where the person lives with it rather than resolving it and moving on.

From these findings then, transition to being a person who lives with chronic pancreatitis, and all that it entails, is a gradual process of assimilation. This resonates with the literature on mastery (Younger, 1991; Younger et al., 1995), transition (Kralik et al., 2006) and transformation (Paterson et al., 1999) where reframing what is normal, relinquishing the hope for a return to a pre-existing state and the adoption of strategies to manage situational alterations are markers of the process. However, studies of various chronic illnesses have indicated that this may take many years or in some cases may continue throughout life and never be resolved (Powell-Cope, 1995; Glacken et al., 2001; Kralik et al., 2006). Whilst it is not being claimed that participants in this study will never achieve a meaningful reconstruction of their self-identity, at the time of the study and despite the passage of time none could be said to have completed this transition.

Figure 6.3: Transition in Chronic Pancreatitis



6.5 Final Interpretation and Discussion

The aim of this hermeneutic inquiry was to develop an understanding of what it means to live with chronic pancreatitis. Through elucidation of my personal and professional pre-understandings, construction of the participants' stories, detailed textual analysis and explication of the themes and sub-themes and incorporation of pertinent and indicative literature, the understanding represented here is that living with chronic pancreatitis constitutes 'enduring disruption'. It was proposed in Chapter 5 that the three unifying categories of enduring physiological disruption, enduring social disruption and enduring psychological disruption that symbolise enduring (permanent or perpetual) disruption represents 'suffering'. Subsequently, in Chapter 6, the second meaning of 'endure', 'to cope with' and/or 'to tolerate' explicated how the participants and their families 'come to know', and 'adjust/manage' through the development of self-management strategies within the overall process of transition from 'well' person to a person who lives with chronic pancreatitis.

Together these interpretations form the whole of 'enduring disruption' that constitute this understanding and represent the meaning of living with chronic pancreatitis. Whilst they have been presented separately for the purpose of explicating the multidimensional nature of 'enduring', in essence, they are interrelated and interdependent (Figure 6.4).

Their interdependency and interrelatedness is bound in and explicated through their mutual relationship. The interpretation of the first meaning of enduring (perpetual and permanent) illuminated the participants' suffering in three forms (related to illness/treatment, related to care, related to existence). These forms of suffering, which vary in intensity and can occur in isolation or simultaneously, comprise the adversity with which the participants have to cope and/or tolerate. Subsequently, the second meaning of enduring (to cope with and/or to tolerate) elucidated the action taken, in the form of self-management strategies, to ameliorate and alleviate their suffering.

This was evident in the increasing proficiency and emerging confidence and control in managing situations related to their illness and treatment. It also characterised progression in the overall transition process, where the strategies for managing the suffering of illness and treatment were incorporated into their daily living. This progression was essentially

underpinned by an acceptance of their permanently altered lives and acknowledgement that a return to their previous way of being was no longer possible.

Moreover, the existence of hope and faith suggests that some participants were beginning to confront suffering related to existence. However, it was also identified that these concepts were fragile and shattered by hopelessness engendered by recurring, intense or intolerable suffering related to illness and treatment, and/or care. Characteristics of these participants' existential suffering could be said to be represented by their inability to emotionally accept themselves as a person with chronic illness, their continued present-orientated state of being and their explications of pervasive existential uncertainty. Thus, progress in the transition process to a redefined self-identity in adversity is hindered by being unable to confront their existential suffering fully.

Finally, even though participants in this study may ultimately achieve a meaningful reconstruction of their self-identity, the nature of chronic pancreatitis means that suffering will never be fully alleviated. Furthermore, the possibility of intensified suffering is ever-present, which for some may mean they may never be able to confront their existential suffering.

This final interpretation presents a new understanding of quality of life for the person who lives with chronic pancreatitis. Within the chronic pancreatitis literature, research on quality of life or aspects thereof, as outlined in the preliminary literature review in Chapter 2, has been confined to a medical discourse that focuses primarily on health decrements in life domains such as physiological, functional, social and emotional. Important points in respect of the definition of quality of life and its operationalisation with quality of life or health-related quality of life instruments arise from such a position.

Quality of life, according to a number of writers, is a multidimensional concept that encompasses a range of objective and subjective aspects that change in relative importance over time and in response to various life experiences (Farquhar, 1995; Anderson and Burckhardt, 1999; Haas, 1999; Niv and Kreitler, 2001; Murphy et al., 2007). However, these authors have also

identified that agreement on a definition and means to measure quality of life have been notoriously difficult to achieve. This, it is argued, is because various researchers approach quality of life from their disciplinary perspectives with the resulting difference in focus (Anderson and Burckhardt, 1999). This is reflected in the numerous studies of chronic pancreatitis cited in Chapter 2, where quality of life tends to be viewed through a physiological lens where the concentration is on identifying and evaluating medical interventions or treatments that improve outcome (health status/functioning). To some extent, it reflects what Anderson and Burckhardt (1999) describe as the conflation of outcome and quality of life where measurement in clinical trials and research continues to focus on physiological dysfunction, functional performance and symptoms. Moreover, the diversity and variety of instruments used as well as the evident lack of conceptual or operational definitions of quality of life not only precludes comparison of the effectiveness of interventions but essentially compromises the value of the contribution of this research to improved patient outcome. Furthermore, although there has been some criticism in the literature that quality of life is too general a term to be useful in health care (Wellard, 1998; Haas, 1999), the adoption of the term health-related quality of life is simply a proxy for medicine's continued focus on health- and illness-related variables (Farquhar, 1995; Anderson and Burckhardt, 1999). Thus, whilst there is recognition of the subjective elements of the concept of quality of life, the focus remains on achieving measurable outcomes.

Whilst it is acknowledged that measuring components of quality of life is an important element of evaluation in clinical trials, the quality of life studies in chronic pancreatitis represent a paradigm whose ontology and epistemology places value on measurement and objectivity. What this means in the context of this study is that the issue of quality of life for those with chronic pancreatitis is objectified through the use of instruments, the domains of which purport to represent the inherent components of life quality. This perspective reduces the subjective perceptions of the participants to empirical measurement that essentially has the ultimate effect of objectifying the experience of the person.

Nevertheless, that living with chronic pancreatitis leads to an altered perception of quality of life from the person that 'was' to the person who 'is', is supported by the findings of this study. This is evident in the suffering related to illness and treatment identified in the interpretation in Chapter 5, which corresponds to the literature reviewed in Chapter 2. However, the suffering related to care and suffering related to existence, point to an embodied, subjective experience that encompasses more than the decrements associated with health status. Moreover, for the participants and their families suffering is situated and contextualised, and is inseparable from their efforts to tolerate it and mobilise coping strategies to modify or minimise its impact. Thus, the meaning of living with chronic pancreatitis for these participants is transition embodied in suffering (Figure 6.4) and essentially reflects the hermeneutic perspective adopted for the study where achieving harmony between the parts and the whole was the criterion for achieving understanding.

The key concepts of enduring, suffering, and transition identified from the findings of this study have been the subject of an increasing proliferation of work within the realms of chronic illness. In respect of suffering, recent and contemporary empirical studies have strived to delineate the concept as it is perceived by the person experiencing it. Efforts have been directed at labelling and explicating 'expressions' of suffering as well as distinguishing the 'what' of suffering (Lindholm and Eriksson, 1993; Arman et al., 2002; Arman and Rehnsfeldt, 2003; Öhman et al., 2003; Arman et al., 2004; Rehnsfeldt and Eriksson, 2004). Key expressions such as loss, threat, alienation, distress, feeling disempowered and loss of dignity are depicted in these studies as being reflective of the concept. Although these works have all been undertaken with persons with various chronic illnesses, their findings support the interpretation in the present study that the participants are suffering. In addition, Eriksson's representation of suffering related to illness and treatment, suffering related to care and suffering related to existence (Lindholm and Eriksson, 1993) provides an explanatory framework for the interpretation that enduring physiological disruption, enduring social disruption and enduring psychological disruption represent the suffering of chronic pancreatitis. Moreover, the finding herein that suffering is more than 'suffering from' and encompasses existential threat is in keeping with its

conceptualisation in Younger's (1995) theory of alienation of the sufferer and Eriksson's (1997) theory of the suffering human being.

In contrast, the praxis theory of suffering developed by Morse and Carter (1996) and subsequently expanded (Morse, 2005) offers a different representation to that proposed in the current study. It is included, however, because 'enduring' is a key concept and a comparison of its representation was undertaken to determine if there was congruency with its emergence in this study. Morse and Carter (1996) conceive that the concepts of 'emotional suffering' and 'enduring' comprise the two broad and divergent stages of suffering that are not only distinct but diametrically opposite. For Morse and Carter (1996) emotional suffering is a distressed state in which emotions are released, whilst enduring is an emotionless state that equates with 'bearing' profound physiological or psychological assault. They perceive that persons move from enduring to emotional suffering when they are tentatively ready to accept their loss or they may oscillate between the two states and progress through suffering in a non-linear way. However, they note that the intensity of each state varies according to the individual's situation.

In this study, the conceptualisation of suffering and enduring as well as their relationship to each other essentially differs from that assigned in Morse's (2005) theory. This is largely attributable to the two-fold interpretation and representation of enduring. Enduring as an attributive adjective describes the nature of the participants' disrupted lives, which in the context of this study comprises the key experiential component of living with chronic pancreatitis and is ultimately interpreted as suffering. While this conception of enduring is novel in the chronic illness literature, as a descriptor it offers a useful semantic for conveying the inherent permanency of living with chronic pancreatitis.

In respect of its second meaning, 'to cope with' and/or 'to tolerate' as it is conceived in this study, there are parallels with Morse's (2005) conception of enduring as 'bearing' or 'getting through' where the person's ability to function is mediated by the intensity of the assault. This is evidenced by the varying coping responses of the participants in this study depending on whether they are in periods of relative stability or experiencing escalating or

salient physiological disruption. However, the findings herein are not congruent with Morse and Carter's (1996) proposition that enduring is an emotionless state. As indicated throughout, the separation of the two-fold meaning of enduring was for the purpose of delineating its multidimensional nature, but in essence they are interdependent and interrelated and the participants' experiences are embodied and inseparable. On reflection, this may be accounted for, in part, by the differing nature of the studies. Whilst this study centred on participants' accounts of living with chronic pancreatitis, with suffering emerging as a key concept, Morse and Carter's (1996) work, which originated in narrative biographies of persons who had suffered acute traumatic events and has since included behavioural observations of those who were suffering, focuses specifically on understanding the phenomenon and illuminating its behavioural cues (Morse, 2005). Thus, the arrangement, meaning and relationship of their key concepts within the construct of suffering is different to that proposed in this study. This reflects the potential for diverse interpretations of phenomena but also highlights the conceptual confusion, acknowledged by Morse (2005), and the difficulty of achieving consensus about abstract, multidimensional, holistic and perceptually subjective concepts.

Despite the differences in the theories and conceptualisations of suffering outlined above, an explicit commonality is the notion that suffering can progress to healing or transformation (Younger, 1995; Eriksson, 1997; Arman and Rehnsfeldt, 2003; Morse, 2005). Other conceptualisations, theories and research that do not specifically label *suffering* as *the* transformative factor describe a course of change or process triggered by chronic illness. Although characterised variously as adaptation (Charmaz, 1991; 1995) biographical disruption (Bury, 1982; Asbring, 2001; Boeije et al., 2002), transformation (Paterson et al., 1999), transition (Kralik, 2002; Kralik et al., 2003; Kralik et al., 2004) and integration (Whittemore and Dixon, 2008), each describes what appears to be a common phenomenon associated with a process of adjustment to chronic illness.

Embedded in this process is the notion of a response to the change enforced by chronic illness that is mirrored in the findings of this study. Longitudinal studies (Charmaz, 1991; 1995; Paterson et al., 1999; Kralik, 2002) highlight

the phasic nature of the adjustment process, where progress towards learning to live with chronic illness occurs over time but is not strictly a chronological trajectory. Although time may be a factor in terms of becoming proficient in the management of illness, deeper psychological and emotional adjustment and altered life construction is complex. Of the many factors that are cited as influencing adjustment, and particularly pertinent to persons with chronic pancreatitis, is a lack of stability in terms of the physical assault of the illness. Thus, achieving mastery, integration, a successful transition or transformation, which in the previous research is identified as a path to regaining the integrity, balance and wholeness of the person is mediated, in part, by the illness itself. At times of salient disruption, the illness demands dominate and have been likened to 'living an illness' (Whittemore and Dixon, 2008), 'extraordinariness' (Kralik, 2002) and 'illness in the foreground' (Paterson, 2001b).

The results of this study identified enduring (to cope with and/or to tolerate) as transition from well person to a person with chronic pancreatitis, corroborating the view that adjustment to chronic illness is phasic. Rooted in this transition, represented as 'coming to know' and 'adjusting/managing', are the active processes undertaken by the participants that signify the work of adjustment mediated by the impact of the illness on their physiological, psychological and social selves.

Previous research also supports the finding that adjustment to chronic illness requires considerable and persistent effort to find a place for illness in the lives of those experiencing it (Boeije et al., 2002; Kralik, 2002; Whittemore and Dixon, 2008). This effort incorporates the behavioural, psychological, emotional and existential work an individual with chronic illness undertakes. The representation in this study is congruent with that of Kralik (2002) where the work of chronic illness takes place within the transition process, and self-management not only incorporates behavioural work associated with managing the condition but also includes the psychological, emotional and existential work associated with 'self'.

That this work is arduous and represents a challenge to self-identity is supported in numerous studies of various chronic illnesses but represented

vividly as 'biographical disruption' and 'loss of self' in the seminal works of Bury (1982) and Charmaz (1983). As indicated in the interpretation in Chapter 6, sustaining a positive identity in the face of disequilibrium caused by disease progression in chronic pancreatitis and associated losses in physiological, psychological and social functioning is difficult and challenges efforts at adjustment. Moreover, that existential work is the most challenging is epitomised by the finding herein that despite the participants' increasing proficiency in the management of their illness, deeper psychological and emotional acceptance of themselves as a person with a chronic illness could not be said to have been achieved.

The challenge of existential work is reflected in the reports of research identified above, where seeking purpose and meaning and re-clarifying beliefs and aspirations is something to be strived for and is presented, almost, as a final step in the process of coming to terms with chronic illness. However, those concerned with transition, transformation and integration counter this with the rider that an end point may never be achieved and that the person should be viewed as 'evolving' rather than determined as being unsuccessful in their efforts to adapt to living with chronic illness (Paterson et al., 1999). For example, Boeije et al's (2002) findings resonate with those of this study where they identified that for persons in the downward phase of multiple sclerosis, biographical recasting or identity reconstruction was almost impossible because of a lack of control over the trajectory of the illness.

However, despite the perceived significance of an unpredictable and uncertain illness trajectory, previous research also highlights a myriad of interpersonal and intrapersonal factors including family, cultural, educational, social, religious/spiritual and healthcare aspects that influence the work of chronic illness. Support and resources, or a lack thereof, are determined to be critical factors in augmenting or diminishing the person's effort to adjust to living with chronic illness (Kralik, 2002; Kralik et al., 2003; Whittemore and Dixon, 2008). The perceived importance of these supports and resources has led these researchers to claim that the illness trajectory alone cannot account for the challenge of adjusting to living with chronic illness.

However, some caution must be exercised in attempting to extrapolate the significance of any or all contextual factors to all chronic illnesses given that many studies have used qualitative methodologies, analogous to that of this study, with data being generated from small, selective, non-random samples over a short period of time, often focussing on one chronic illness and undertaken within a particular healthcare context. For example, whilst the findings of the current study identify that social support (information, practical, emotional) and resources or a lack of them, facilitate or constrain aspects of the participants' adjustment to and management of chronic pancreatitis, they are essentially particularised to this group and inferences about the weighting of various factors can only be made within these parameters. Therefore, whilst there is a requirement for research that identifies commonality of chronic illness experience, there is also a need for recognition that elucidating disease specific illness experiences does not necessarily confer transferability to other contexts or settings.

6.6 Conclusion

This review of the findings of this study in light of previous research has highlighted that there are co-existing similarities and differences between the experiences of those living with chronic pancreatitis and various other chronic illnesses. In this study, the meaning of living with chronic pancreatitis is enduring disruption, with suffering and transition comprising its two constitutive concepts. Whilst this particular interpretation and representation is new, there are parallels with previous depictions of suffering and transition.

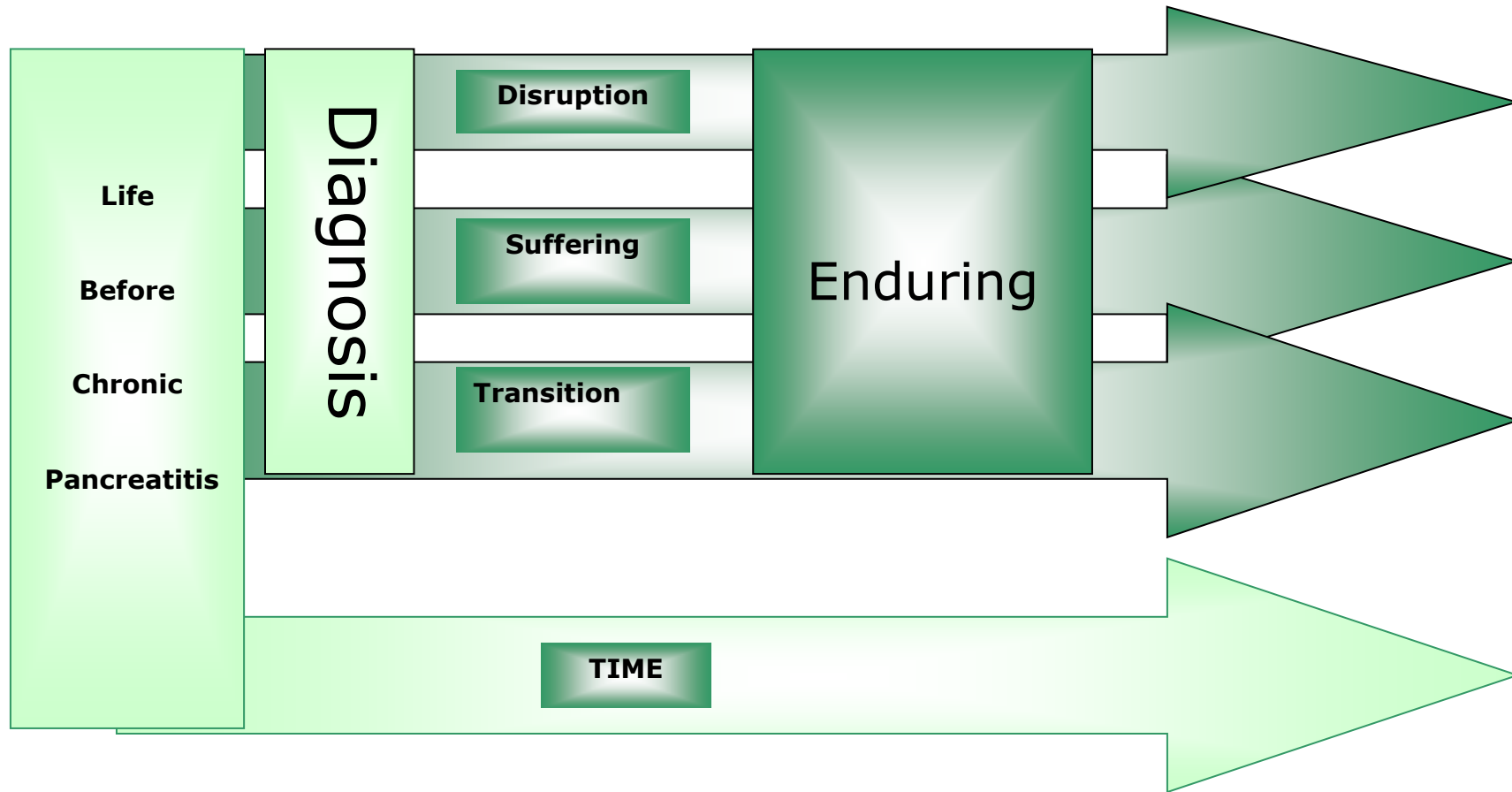
Primarily, previous research supports the interpretation that suffering is an appropriate concept to represent the enduring physiological, psychological and social disruption of chronic pancreatitis for the participants in this study. Moreover, these depictions shed light on the suffering related to illness and treatment, care and existence that these participants experience and offers further validation of Eriksson's model outlined above. Explicating suffering in this way extends and offers a new perspective on life quality in chronic pancreatitis.

In addition, previous research supports the interpretation that transition captures the process of adjusting to living with chronic pancreatitis. Moreover, it reflects the efforts the participants are making to strive for an acceptable quality of life. In this sense, the work of living with chronic pancreatitis is more than the behavioural work of disease management but encompasses the psychological, social and vocational and existential work within the person's context and situation. This study has begun to identify some of the active processes undertaken by people who live with chronic pancreatitis. Further research in this area is needed in order to specify the work of the illness experience of chronic pancreatitis as distinct from that undertaken in other chronic illnesses. Additionally, such research may provide direction for healthcare professionals in their assessment and designation of interventions that maximise the potential for achieving a life quality that is acceptable to the individual living with the condition.

Finally, supplementing previous quality of life research with work undertaken from an emic perspective expands understanding of the meaning of the complex and multidimensional experience that is living with chronic pancreatitis. Ultimately, this study offers support for Benner's (1985:13) contention that 'objectification and subjectification on their own cannot capture the lived experience of health and illness because human beings are never fully object or fully subject'. Therefore, there is a need for both perspectives in attempting to obtain the complete picture of the meaning of living with chronic pancreatitis.

The following chapter, the final one of this thesis, discusses the implications and recommendations of Chronic Pancreatitis as Enduring Disruption for practice, research and education.

Figure 6.4: Chronic Pancreatitis – Enduring disruption



CHAPTER 7 – IMPLICATIONS AND RECOMMENDATIONS

7.1 Introduction

This final chapter discusses the implications and recommendations of Chronic Pancreatitis as Enduring Disruption for service provision, practice, education, and research. However, in determining the appropriateness of these implications and recommendations, the reader is asked to situate them within the conditions under which the study was undertaken, the challenges encountered in its conduct and its overall integrity as identified in Chapter 4.

7.2 Implications

This is the first study in Ireland that has included those who live with chronic pancreatitis and their families. Although it is important to recognise that the findings achieve idiographic generalisability only, in that their pertinence is limited to those involved in the study, it is posited that there are implications for the care and management of all of those diagnosed with the condition. Furthermore, it is suggested that the research approach undertaken extends and offers substance and insight to the findings of international studies that have used recognised quality of life instruments by facilitating exploration of why elements of quality of life are compromised in those with chronic pancreatitis.

The findings of the study are represented in the understanding that the meaning of living with chronic pancreatitis constitutes enduring disruption, which it has been proposed has a two-fold meaning. Enduring disruption, meaning permanent or perpetual symbolises suffering, which is elucidated in three forms; suffering related to illness and treatment, suffering related to care and suffering related to existence. These three forms of suffering explicated in the configuration and interrelationship between enduring physiological disruption, enduring social disruption and enduring psychological disruption were determined to represent the '*what*' of suffering in chronic pancreatitis. The second meaning of enduring, (to cope with and/or to tolerate) represented as transition from 'well' person to a person with a chronic pancreatitis and incorporating 'coming to know' and

'adjusting/managing' signify the active processes of ameliorating or alleviating suffering.

There are a number of implications arising from these findings. Primarily, this study, using a subjective lens, offers an alternative frame from which to view living with chronic pancreatitis. The previous quality of life research in respect of chronic pancreatitis has been undertaken from a biomedical perspective, which offers but one dimension of the meaning of living with the condition. Moreover, quality of life research can only provide standardised information about general patterns and ultimately cannot anticipate a person's unique response to their illness. Thus, the results of this study represent a challenge to the emphasis on the management of the pathophysiological processes of disease and treatment that is decontextualised from the person's everyday living. Additionally, it calls for a healthcare discourse that not only acknowledges the progressive nature of chronic pancreatitis and the prolonged and ongoing physiological impact but also incorporates, holistically, the psychological, social, emotional and existential work of living with the illness. If this is to be achieved there are implicit implications for service provision within the healthcare and social welfare systems in Ireland.

Yet, it was evident in the literature review undertaken prior to the conduct of the study that little is known about people who are diagnosed with chronic pancreatitis in Ireland. It was highlighted that prevalence data regarding chronic pancreatitis does not exist although statistics regarding hospital inpatient episodes are available. Nonetheless, in reports and publications chronic pancreatitis is subsumed within the ICD codes of other pancreatic and biliary conditions and the information gleaned could only be obtained following a personal request to the Economic and Social Research Institute (ESRI). Regardless of the rationale for publishing data in this way, the implication for those living with chronic pancreatitis is that it is likely to continue to remain unknown.

Furthermore, many of the participants in this study experienced occupational disruption that compromised their current and future social functioning. Of particular note was their age range, which was younger than that published in international studies. Whether this is a reflection of a trend in Ireland is

unknown but is worthy of consideration when ascertaining the implications of a diagnosis of chronic pancreatitis.

Therefore, gaining recognition at policy and strategic level must begin by considering what can be done through education, research and practice that will raise the profile of the condition, so that the biopsychosocial needs of those with chronic pancreatitis are incorporated into the overall strategic and policy developments of those with chronic illnesses in Ireland.

It is suggested that the process of reconstructing chronic pancreatitis must begin at the point of engagement with the health service and by association those working within it. The findings indicate that the suffering related to the illness and the attendant treatment regimes cause considerable decrement in physiological, social and psychological functioning. However, rather than the impact of these being alleviated or even ameliorated through contact with and input from the healthcare system, they are compounded by interpersonal, intrapersonal and infrastructure situations therein.

The experiences of those in this study mirror the known problems with early diagnosis of chronic pancreatitis. Interpretation and differential diagnosis of the acute symptoms experienced by the majority of patients in this study often did not include pancreatitis in any form. This resulted in marked physiological decrement and aggravated and prolonged suffering by the participants, which was further compounded by misdiagnosis and extended waiting for investigations, consultations and/or treatment throughout the whole of the pre-diagnostic phase.

The findings indicate also that the participants frequently feel disempowered, uncared for or experience loss of dignity as a result of their interactions with the healthcare service and those who work within it. Many of these appear to be located in the perception of the relationship between alcohol and chronic pancreatitis. That some healthcare professionals lack knowledge and insight into the progressive nature of the condition regardless of alcohol consumption is evident in the labelling and stereotyping experienced by those with chronic pancreatitis. This results in a reluctance to engage with healthcare

practitioners who are deemed to be prejudicial or who are perceived as lacking the appropriate knowledge and skills.

One consequence of this is that in the transition from 'well' person to a person with a chronic illness, the development of self-management strategies largely occurs independently of healthcare providers. Yet, initially, many patients do not know what strategies to adopt and are unable to gauge if those they do employ are effective or ineffective as the infrastructure and interpersonal elements within the healthcare system hinder engagement. With ongoing monitoring and treatment being located within the domain of the hospital and for the most part within the confines of the outpatient appointment, appropriate support and education is limited at best. Furthermore, within the consultation, the focus is directed mainly at pathophysiological assessment where the voice of the healthcare professional continues to dominate and the emphasis on a compliance model inhibits patient participation, empowerment and involvement in decision-making. In addition, as their emotional, psychological and social needs were unlikely to be raised in consultations with healthcare professionals they were perceived by the participants to be unimportant and therefore not addressed. Thus, the burden of emotional care falls mainly on social support networks within the family, which in some cases, leads to conflict and tension within relationships. This means that with the exception of the service provided by their treating consultant and general practitioners, those with chronic pancreatitis can be isolated and unsupported in the day to day management of their living.

In addition, there does not appear to be standard practices for referring patients to support services such as pain specialists, dieticians, social work and counselling for alcohol dependence or emotional support. For the majority then, strategies directed at handling the pain, gastrointestinal disturbances, food intolerance, incapacitating fatigue and loss of physical strength are learned experientially. Moreover, while there is merit for some treatments to be undertaken by those with specialist skills in pancreatology, situating ongoing monitoring within the hospital setting not only places additional pressure on an overloaded system but causes frustration and discomfort to patients who are required to travel long distances for what are deemed to be, in many cases, unsatisfactory consultations.

These emergent understandings of the experience of transition in chronic pancreatitis have implications for the manner in which healthcare is accessed but are also of import to the promotion of self-care management strategies in those who live with it. These issues demand consideration of how patients are informed and educated about their condition and how ongoing support can be facilitated through engagement in the healthcare encounter. If the service is to be responsive to the needs of those in their care then a fundamental move away from service-centred and specialist provision to one that is person-centred and locally delivered is necessary. The following recommendations for practice and service provision, education and research are made in light of this view and in the contention that the findings indicate that those with chronic pancreatitis are not receiving optimal care in terms of education and support.

7.3 Recommendations for practice and service provision

7.3.1 Service provision (Strategic and Policy Level)

It is recommended that:

- Chronic pancreatitis is included on the national list of prescribed illness or disabilities that would entitle those with the condition to the services afforded others with recognised chronic illnesses.
- It is suggested that a system be established for the collection of incidence and prevalence data on chronic pancreatitis by the Department of Health and Children. This could be general practitioner based using codes that are linked to ICD codes.
- Written information leaflets and support documentation be developed in partnership with people with chronic pancreatitis and using 'patient narratives'. It should also include resources available such as telephone numbers or appropriately evaluated online web support should also be included.
- Facilitate the development of a Patient and Family Support and Education Group for Pancreatitis (Acute and Chronic) based in Ireland.

7.3.2 Service provision (Operational and Local level)

It is recommended that:

- Integrated, multidisciplinary care packages that span both the acute and primary care sectors are developed.
- Mechanisms for liaising with community-based services including General Practitioner, Public Health Nurses and Practice Nurses be established to ensure seamless transition and appropriate support is in place prior to discharge from hospital.
- Engagement with Public health and Practice nurses to determine measures needed to provide local ongoing support and education for those with chronic pancreatitis.
- A telephone information and advice service is provided for staff in the community sector who may require support in the ongoing management of the patient with chronic pancreatitis.
- Consideration is given to establishing specialist nurse led clinics that coincide with outpatient clinics, for assessment and reconfiguring of care packages in conjunction with the patient.

7.3.2 Service provision (Professional Level)

It is recommended that:

- A web-based information and support service is established for those with chronic pancreatitis, which could also include a forum for healthcare staff. Ideally this should be constructed, monitored and overseen by a professional body such as the Irish Gastroenterology Association.
- That the Irish Endoscopy Nurses association is expanded to incorporate gastroenterology or an Irish Gastroenterology Nurses association be founded to raise the profile of gastroenterological nursing and to provide a dedicated forum for disseminating issues related to chronic pancreatitis.

7.3.3 Nurses working in clinical practice

It is recommended that:

- Nurses genuinely engage with individuals and encourage active participation in the assessment of their needs and identification and development of self-management strategies.
- A move to a model of self-management that is broad, contextual and has meaning for the individual. It should go beyond the technical and medical and incorporate the patient's abilities, interests and concerns.

7.4 Recommendations for education

7.4.1 In-service education

It is recommended that:

- In-service educational programmes are developed to address the needs of the multidisciplinary team caring for those with chronic pancreatitis. This should include modern theories of chronic pancreatitis, contemporary management and treatment of the condition and developments in research that may influence future management.
- In-service education incorporates exploration of prevailing attitudes to alcohol consumption in those with chronic pancreatitis as well as education and training in responding in a non-judgemental and competent manner.

7.4.2 Nurse education

It is recommended that:

- Nursing curricula at under-graduate level integrate the teaching of the care and management of those with chronic pancreatitis with aspects of education that address chronicity, chronic illness and rehabilitation.
- Across all programmes and modules, teaching should focus on empowerment models of chronic illness rather than emphasising compliance models.

- Programmes should also give equal significance to developing knowledge and understanding of the psychological and social factors which influence health care behaviours as is given to pathophysiological knowledge of the disease.
- Since Public Health and Practice Nurses are becoming increasingly central to effective chronic disease management in the primary care setting, post-graduate Diploma/Masters and/or stand alone modules in Practice Nursing/Community Nursing should incorporate the needs of those with chronic pancreatitis when considering the over-arching principles of chronic illness management.

7.5 Recommendations for research

The recommendations for research proposed below are phased in that the conduct of some of the proposed studies will depend to some degree on the completion of others.

It is recommended that:

- Given that this study focussed on those in the care of one hospital consultant, a wider study incorporating other centres should be undertaken in order to gain a more comprehensive picture of the experiences of those with chronic pancreatitis in Ireland. Using the three unifying categories of enduring physiological disruption, enduring psychological disruption and enduring social disruption, a semi-structured questionnaire can be devised that will establish whether or not experiences have some consistency.
- The current study is expanded to establish if the coping strategies identified in the transition from well person to a person living with chronic pancreatitis are reflected within the wider population of people with the condition.
- A study that examines fatigue in chronic pancreatitis be conducted. While there appears to be some correlations with chronic fatigue and how it is represented in other chronic illnesses, further clarification into its manifestation in chronic pancreatitis is needed since the manner in which it is experienced is not standard across all chronic illnesses. This would facilitate the development of effective intervention strategies.

- Research is carried out with healthcare professionals to determine their knowledge and skills about chronic pancreatitis and their attitudes toward those with the condition.
- A study is conducted that examines the burden of care on family members and their role in the support of those with chronic pancreatitis.

7.6 Contribution to knowledge

In keeping with its original intention and using Gadamerian philosophical hermeneutics, this study has proposed one construction of the meaning of living with chronic pancreatitis. In so doing, it has made a contribution to understanding orientated and reflexive nursing knowledge from an interpretive stance and has offered an alternative perspective to the traditional quality of life research in chronic pancreatitis. Through explication of the meaning of living with chronic pancreatitis, it has illuminated a previously unknown area of nursing knowledge by giving voice to the participants' storied living with illness. The proposed framework for understanding the meaning of living with chronic pancreatitis not only identifies what is important to the participants, as subjective human beings but highlights the means by which they adjust to living with their illness. This has widened the potential understanding that could inform healthcare policy, strategy and practice.

The study, also contributes to the knowledge of chronic illness by adding the experiences of a very specific group of people with an illness that, to date, is neither recognised nor researched within the chronic illness literature. The inherent chronicity of chronic pancreatitis was corroborated through the parallels with research into other chronic illnesses but disparities in experience were also highlighted. Thus, this study adds to the debate that over-emphasis on commonality across illness experiences can render diversity invisible (Thorne et al., 2002a).

In addition to illuminating the meaning of participants' experiences of living with chronic pancreatitis, this study also extends methodological understanding and knowledge of undertaking a study using Gadamerian

philosophical hermeneutics. Through explication in Chapter 4 of Gadamer's philosophical concepts and subsequently delineating how they impacted on the decisions of data collection, data analysis, interpretation and integrity, this study has contributed to providing methodological direction by outlining a systematic approach for reaching understanding. In addition, by focussing the study within Gadamerian hermeneutics as distinct from a combined Heideggarian/Gadamerian approach undertaken in much of the nursing research, philosophical congruence was achieved. This provides some clarity in the continuing debate about philosophical misunderstanding in nursing studies.

Finally, this study identified that the emphasis on language, genuine conversation and dialogue within Gadamerian hermeneutics has the potential to facilitate the production of valid knowledge of our qualitative human reality. The interview or conversation is the conduit for the construction of knowledge between the persons involved and it is through genuine conversation that fusion of horizons occurs resulting in a new understanding of the subject matter. In the interlocution of the interview and through the craft of genuine conversation knowledge that is both relational and contextual is co-constructed (Kvale and Brinkmann, 2009).

7.7 Study Limitations

In addition to the challenges encountered and delineated in this report of the study, some limitations were identified. Of these, a number were common to many interpretive research studies whilst others were particular to this one.

Similar to other interpretive studies that use interviews, the participants' expositions of their living are representations and reconstructions of their experiences at a particular point in their lives. As a result, the interpretation proposed herein could not be said to represent the whole of their living because subsequent experiences would influence their reflection and understanding. In addition, because knowledge is co-constructed within the dyad of the interviewer and interviewee where the conversation proceeds by way of question and answer, it is likely that a different dyad at another point in time would result in an alternative interpretation. For example, the final

construction in this study is a composite of the participants' accounts of their living, my pre-understandings, my interactions with the participants, the chosen method of analysis, comparison within and between all sources of data and across the literature and my understanding of the themes as they emerged. In the same way, another researcher would bring his/her own pre-understandings that would not only influence the interpersonal relationship with the participants but would impact on the decisions made and the ultimate interpretation of meaning. Therefore, whilst the interpretation presented here is deemed to be rigorous within the confines of this study, the implications of the findings can be tentative only.

In respect of this study, whilst Gadamer offered insights into how one might develop a deep understanding of texts he did not offer a method for achieving it. Additionally, within the literature methods of data collection and data analysis, in particular, are not adequately described because of the various interpretations of hermeneutics, its sometimes inaccurate conflation with phenomenology and the failure to differentiate between the philosophies of Heidegger and Gadamer. As a result, the methodological decisions made in this study were influenced by my interpretation of Gadamer's philosophical concepts and my decisions on how best to incorporate them into the practical activity of undertaking a research study. Thus, throughout the study, there was potential that I may have misunderstood.

Other limitations of the study were related to the sample and the manner in which participants were recruited to the study. Primarily, the sample was confined to patients in the care of one hospital consultant in one institution, which could be seen as limiting in terms of the transferability of findings to other groups and settings. Additionally, some patients had been referred to the consultant from regional hospitals because of his expertise and it may be that the sample comprised participants whose illness experiences were more acute than the general population of people with chronic pancreatitis.

In terms of recruiting to the study, even though it was estimated, by the consultant, that there were approximately 75 people in his care with a diagnosis of chronic pancreatitis, it was not possible to recruit from this number. This was because the database used to send invitations to participate

in the study only contained the names of those who had been hospitalised in the previous two years. Thus, potential participants who may have achieved relative stability and had not been hospitalised were excluded.

Although, initially, some invitations were extended to potential participants in the outpatients' department, ultimately, this proved to be an unreliable method of recruiting as it depended on the ability of the pancreatic biliary nurse specialist to be present throughout the clinic. Even though these factors were unknown prior to commencing recruitment, on reflection, supplementary information in the form of a poster and letters inviting participation could have been placed in the Outpatients' Department.

In respect of inviting family members to participate, it may have been possible to recruit more numbers if I been more flexible in my approach. For example, I could have indicated in the invitation to participate that joint interviews could be undertaken and, as in the case of one woman for whom the recording equipment was a barrier, I could have resorted to field notes.

7.8 Summary and conclusion

The final chapter in this thesis explored the implications of the findings of this study and outlined recommendations for service provision, practice, education and research.

Overall, the findings provide preliminary evidence of the issues that underpin compromised quality of life of people with chronic pancreatitis in Ireland. Essentially, it gives voice to the experiences of those living with a condition that has devastating physiological, psychological and social consequences and represented here as 'enduring disruption'. It is hoped that consideration of how the recommendations can be implemented will mark the beginning of a process of addressing the plight of this previously hidden group.

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APPENDICES

Appendix 1: Consultant approval to access sample for the study

Patricia Cronin,
Lecturer in Nursing/MSc Course Co-ordinator
School of Nursing & Midwifery
Trinity College Dublin
24 D'Olier Street
Dublin 2

13th June, 2005.

Dear Tricia,

It was good meeting you recently regarding the study we discussed for patients with chronic pancreatitis. Please co-ordinate with ~~the Nurse Specialist in~~ the Nurse Specialist in Pancreatico-Biliary diseases with regard to identifying the suitable patients. Once we have the list there will be absolutely no problem for you seeing the patients and entering them onto the study. Please let me know when ethical approval is given so we can commence.

Looking forward to working with you.

Kind personal regards,

Yours sincerely,



Appendix 2: Institutional Ethics Approval to undertake the study

Ms. Patricia Cronin
School of Nursing and Midwifery
Trinity College
24 D'Olier Street
Dublin 2

July 28th 2005

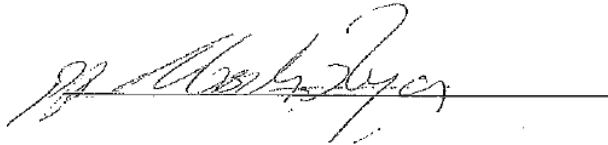
Re: living with chronic pancreatitis

Please quote this reference in any follow-up to this letter: 2005/26/20 Chairman's Action.

Dear Patricia,

The proposal to conduct the study under the above title has been reviewed by the Vice-Chairman of the SJH/AMNCH Research Ethics Committee. On behalf of the Committee the Vice-Chairman has given ethical approval to this proposed study.

Yours sincerely,



Appendix 3: Participant Information Sheet

Participant Information Sheet

1. Name of researcher: Patricia Cronin

2. Title of study: Living with chronic pancreatitis

3. Introduction: I would like to invite you to consider taking part in my research study, which is about exploring your story of living with chronic pancreatitis. The study is being undertaken as part of a PhD. I am a qualified nurse and I have some experience of working with patients who have pancreatitis. I believe the study is important in helping health care staff gain a better understanding of the impact chronic pancreatitis has on your life. You may benefit from the opportunity to reflect on and discuss your experiences. The following information is designed to enable you to gain an understanding of the study before you formally agree to take part. Be sure to ask any questions you have about the study, your part in it and/or the information contained in this information sheet.

4. Procedures: In order to take part in the study you must be over 18 years of age and have been told you have chronic pancreatitis. You can take part in the study in the following ways:

- **Meet with me to tell me your story of living with chronic pancreatitis**

AND/OR

- **Keep a written diary of your everyday life**
- **Meeting with me to tell me your story of living with chronic pancreatitis**
- This will mean meeting with me more than once (maybe 2 or 3 times) over a few months. I will meet you at a time and a place that is best for you. Each meeting will last approximately 2 hours. I do not expect you to travel to meet me – I will come to you. We can meet in a public place or wherever you feel most comfortable.
- I do not have any specific questions that I need answered and I will not be using a questionnaire. I am interested in whatever you want to tell me about your life and any aspect of living with chronic pancreatitis. We will talk for as long as you want. If you change your mind at any time you can stop and you do not have to meet me again.
- Each interview will be tape-recorded using a small MP3 player. I will use this so that I do not have to take notes and I can concentrate on what you are telling me. When the interview is finished I will transcribe

the interviews from the player. These transcripts will be sent to you in the post so that you can read them. If you are not happy with certain aspects I will remove them. If you mention the names of people or places in the interview these will be removed so that their identity will not be known.

- **Keeping a written diary of your everyday life**
- You may like to meet me but in-between our meetings you might like to keep an account of the things that happen in your life on a day to day basis. If you would like to keep a diary I will supply you with one. You can write in it as often as you like, you can write whatever you want and in whatever way you want. There are no rules except that you are willing to let me read it later. I will ask you to write in it for a period of six months.
- If you decide you would like to take part in the study and tell your story but you do not want to meet with me, you can choose to write in a diary only.
- **Close family member**
- **ONLY IF YOU ARE WILLING** I would also like to invite a member of your family to take part in ONE interview but where you would also be there. This is because I also want to see what their views are. This family member will be the person identified by you. I will ask you when we meet for the first time if you are willing to do this. If you do not want to I will not ask again.

5. Benefits: There are no direct benefits of you participating in the study although some people do find it beneficial to talk about their experiences. It is hoped that the knowledge gained from the study will help identify areas where patients with chronic pancreatitis and their families will benefit from improved support. I will pay any expenses incurred by you as part of taking part in the study.

6. Risks: There are no foreseeable risks to you associated with participating in this study. However should you wish to stop any of our conversations because you are feeling discomfort you are free to do so at any time

7. Confidentiality: Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone. I will be the only person to have access to the tapes and your identity will remain anonymous throughout. The study data will be coded so they will not be linked to your name. Your identity will not be revealed whilst the study is being conducted or when the study is reported or published or if the data is used in future studies. All study data will be collected by me and will be stored in a secure place and not shared with any other person.

8. Compensation: This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

9. Voluntary Participation: If you agree to participate in the study you will be asked to sign a consent form indicating that you are willing to take part. Your participation is entirely voluntary, you are under no obligation to participate and you may withdraw, without question, at any time. Your care and relationship with the health care team will not be affected by withdrawal.

10. Permission: The proposed study has received ethical approval and permission to undertake the study has been obtained from the hospital and your consultant.

11. Further information: You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Patricia Cronin who can be telephoned at If I learn of important new information that might affect your desire to remain in the study, you will be informed at once.

Thank you for taking the time to read this information sheet. I will meet with you personally to discuss any aspects which require further explanation.

Appendix 4: 'Expression of interest' slips

What should I do now?

- **If you do not wish to take part in the study, you do not need to take any further action**
- **If you are interested in the study please complete the slip below**
- **Return it in the Stamped Addressed Envelope provided**
- **I will contact you by telephone and speak with you or arrange to meet with you to discuss the study and answer any questions**
- **If, having had your questions answered, you wish to take part in the study, I will arrange a time and place to meet with you to get your written consent.**
- **Even after signing the consent you have the right to withdraw from the study, without question, at any time in the future.**

Detach here

- **I would like some more information about the study**
- **I am interested in taking part in the study**

NAME:.....

CONTACT TELEPHONE NUMBER:.....

BEST TIME OF DAY TO TELEPHONE:.....

Appendix 5: Informed Consent Form

INFORMED CONSENT FORM

Project: Living with chronic pancreatitis

Principal Investigators: Patricia Cronin

BACKGROUND: The purpose of this study is to explore with patients their experiences of living with their diagnosis of chronic pancreatitis. The information gained from the study will enable a better understanding how chronic pancreatitis affects physical, psychological and social well-being. The study has been approved by the hospital ethics committee and involves no foreseeable risks or harm to you.

Your participation in the study is entirely voluntary, you are under no obligation to participate and you may withdraw, without question, at any time. Your care and relationship with the health care team will not be affected by withdrawal.

Procedures:

- In order to take part in the study you must be over 18 years of age and have been told you have chronic pancreatitis. As the study is about living with this condition it is important that you are willing to talk about your experiences and feel able to do so.
- The information gathered in the study will all be based on one-to-one interviews conducted on possibly three occasions over a period of several months. The timing of each interview will be negotiated with you and will they will last as long as you are willing to talk to me. An interview schedule or questionnaire will not be used. You will be able to discuss any aspect/s of your experiences that you choose and any questions I ask will be related primarily to what you tell me.
- The interviews will take be conducted in a place and at a time that is convenient for you. If at any point you wish to terminate any of our interviews you are free to do so without question.
- The transcripts for each interview will be returned to you for agreement and any aspects with which you are not happy will be removed. The final findings/results will also be returned to you in order for you to tell me whether I have adequately represented your experiences.
- If you are willing to keep a written account of your everyday experiences in between our meetings I will supply you with a diary which I will ask you to share with me.

DECLARATION:

I have read, or had read to me, this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I have received a copy of this agreement.

I understand I may withdraw without question from the study at any time and my withdrawal will not affect my future care.

PARTICIPANT'S NAME:.....

CONTACT DETAILS:.....

PARTICIPANT'S SIGNATURE:

Date:.....

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE:..... **Date:**.....

Appendix 6: Family Information Sheet

PARTICIPANT INFORMATION SHEET

1. Name of researcher: Patricia Cronin

2. Title of study: Living with chronic pancreatitis

3. Introduction: I would like to invite you to consider taking part in my research which is part of a study that is exploring the experience of living with a chronic pancreatitis. The study is being undertaken as part of a PhD. I am a qualified nurse and I have some experience of working with patients who have pancreatitis. I believe the study is important in helping health care staff gain a better understanding of the physical, psychological and social impact chronic pancreatitis has on a person's life and that of their family.

This part of the study is about exploring with you, your experiences of living with or caring for a family member who has chronic pancreatitis. You may benefit from the opportunity to reflect on and discuss your experiences. The following information is designed to enable you to gain an understanding of the proposed study before you formally agree to participate. Be sure to ask any questions you have about the study, your part in it and/or the information contained in this information sheet.

4. Procedures: In order to take part in the study your family member who is already part of the study, has agreed that I can approach you. You must be over 18 years of age and be living with your family member who has chronic pancreatitis. As the study is about living with this condition it is important that you are willing to talk about your experiences and feel able to do so.

I would like to interview you about your experiences. The information gathered in the study will be based on an interview at which your partner/family member will also be present. The timing of the interview will be negotiated with you and will last as long as you are willing to talk to me. An interview schedule or questionnaire will not be used. You will be able to discuss any aspect/s of your experiences that you choose and any questions I ask will be related primarily to what you tell me.

The transcript of the interview will be returned to you for agreement and any aspects with which you are not happy will be removed. The final findings/results will also be returned to you in order for you to tell me whether I have represented your experiences properly.

5. Benefits: There are no direct benefits associated with you participating in the study although some people do find it beneficial to talk about their experiences. It is hoped that the knowledge gained from the study will help identify areas where patients with chronic pancreatitis and their families will benefit from improved support.

6. Risks: There are no foreseeable risks to you associated with participating in this study. However should you wish to stop our conversation because you are feeling uncomfortable you are free to do so at any time. I realise that at times you or your partner/family member may not agree about some aspects of your experiences. In order to avoid any upset or distress, we will meet beforehand to agree how we will deal with any sensitive topics.

7. Confidentiality: Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone. An audio-tape will be used to record our conversations so that I can listen and concentrate on what you are saying. . I will be the only person to have access to the tapes and your identity will remain anonymous throughout. The study data will be coded so they will not be linked to your name. Your identity will not be revealed whilst the study is being conducted or when the study is reported or published or if the anonymised data is used in future studies. All study data will be collected by me and will be stored in a secure place and not shared with any other person.

8. Compensation: This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

9. Voluntary Participation: If you agree to participate in the study you will be asked to sign a consent form indicating that you are willing to take part. Your participation is entirely voluntary, you are under no obligation to participate and you may withdraw, without question, at any time. Your care and relationship with the health care team will not be affected by withdrawal.

10. Permission: The proposed study has received ethical approval and permission to undertake the study has been obtained from the hospital and your consultant.

11. Further information: You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Patricia Cronin who can be telephoned at If I learn of important new information that might affect your desire to remain in the study, you will be informed at once.

Thank you for taking the time to read this information sheet. I will meet with you personally to discuss any aspects which require clarification or further explanation.

Appendix 7: Family Informed Consent Form

INFORMED CONSENT FORM

Project: Living with chronic pancreatitis

Principal Investigator: Patricia Cronin

BACKGROUND: The purpose of this study is to explore with patients their experiences of living with their diagnosis of chronic pancreatitis. Interviewing a partner or family member about living with and/or caring for their relative is considered an important aspect of the overall study. The information gained will enable a better understanding of how chronic pancreatitis affects physical, psychological and social well-being. The study has been approved by the hospital ethics committee and involves no foreseeable risks or harm to you.

Your participation in the study is entirely voluntary, you are under no obligation to participate and you may withdraw, without question, at any time. Your care and relationship with the health care team will not be affected by withdrawal.

Procedures:

You will be interviewed using a formal unstructured approach on one occasion and will take place at a time and place that is convenient for you. The interview will be recorded using an audio-tape but your identity will remain anonymous throughout. The study data will be coded so they will not be linked to your name. Your identity will not be revealed whilst the study is being conducted or when the study is reported or published or if the anonymised data is used in future studies. All study data will be collected by Patricia Cronin and will be stored in a secure place and not shared with any other person.

If at any point you wish to terminate any of our interviews you are free to do so without question.

DECLARATION:

I have read, or had read to me, this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I have received a copy of this agreement.

I understand I may withdraw without question from the study at any time and my withdrawal will not affect my future care.

PARTICIPANT'S NAME:.....

CONTACT DETAILS:.....

PARTICIPANT'S SIGNATURE:.....

Date:.....

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE:..... **Date:**.....

Appendix 8: Examples of Participants' stories

1.0 Story 1.

1.1 Interviews and Reflection

In all **A** and I met four times, the first meeting being an introductory one for the purpose of discussing **A's** participation in the study and obtain his written consent if he indicated a willingness to be included. The three formal interviews were conducted in a hotel over a period of three months. The total time of formal recording was 4 hours and 40 minutes.

I was anxious yet excited about my introductory meeting with **A**. This, for me constituted the beginning of the study and I was not only keen to commence but I was anxious that I made a good impression and that **A** would be willing to be part of what I was trying to do.

Our introductory meeting was in a public house that was convenient for him. Although the venue was his suggestion, my pre-understanding of the relationship between alcohol and chronic pancreatitis was at the fore-front of my mind and I was concerned about meeting in a pub. What would he drink? What should I drink? Would he be comfortable? I realised subsequently this discomfort was mine alone and I had to consciously suppress my misgivings to ensure he did not become aware of how I was feeling. His own demeanour suggested that the meeting place was not an issue of concern for him.

During our first meeting there was a focus on situating **A's** living with chronic pancreatitis. He began by telling me how he came to be diagnosed with chronic pancreatitis. He then addressed the main impact the condition had on his life. The second interview began by focussing on how **A** had been feeling over the previous two and a half months. Although a primary purpose of the second interview was on clarification of discussions in the first interview, **A's** experiences during the intervening time was considered significant to his story of how he lived with chronic pancreatitis. The third interview took place one week after the second at the same venue. This was at **A's** suggestion as he felt he wanted to 'finish' the telling of his story. Although closure was achieved by the end of our dialogue, he offered that he would be willing to speak with me again if I wished.

My immediate impression was that **A** was very young to have chronic pancreatitis. I was also struck by his physical appearance – he was very thin and pale. This assessment contributed to my unwillingness to impose on him in any way and I found myself continuously reiterating that his comfort was paramount.

I was conscious throughout our three meetings that he appeared to be in some physical discomfort. When asked, he said he was in pain but that it was a normal condition for him. I was often conscious of a sense of guilt associated with a perceived imposition that might exacerbate his being unwell. This was intensified by a two and a half month gap between the first and second interviews during which time I tried, unsuccessfully to contact him. When we did speak eventually he explained he had been unwell and one of his strategies in managing these episodes was to minimise contact with

others. He said that he could not talk about chronic pancreatitis when he was feeling physically bad.

My reflections on the process of our dialogues generated mixed feelings. My impression was that **A** was able and articulate in describing what had happened to him and how he came to be diagnosed with chronic pancreatitis. However, I perceived that he objectified his experiences and he offered little in terms of his emotional response to his experiences. He was 'matter of fact' in much of his conversation. During our first dialogue I became aware of this but did not pursue it as I was conscious that we were still at the stage of being virtual strangers. There was a greater sense of ease with each other in the second meeting therefore I did begin to ask affective questions to which he responded.

I was also very conscious of my own performance in the interactions. My pre-understandings about chronic pancreatitis were very much to the fore and in some areas I felt I was seeking their confirmation. I noticed that on several occasions I referred to the literature when making a point or asking a question. On reflection, I surmised that this was a sub-conscious effort on my part to affirm my credibility with **A** and in a sense was part of reassuring him that I knew about the condition of chronic pancreatitis.

1.2 A's story

1.2.1 The beginning

A is in his 30's and had been diagnosed with chronic pancreatitis six years previously. He estimated he had the condition for approximately one year before it was accurately diagnosed. He had three acute attacks in that period but they had been mis-diagnosed as gastritis.

A's first attack occurred in 1999 soon after he returned to live in Ireland. He did not know what was happening to him and called his GP but a diagnosis of pancreatitis was not suspected. **A** thought it might be food poisoning. He had two subsequent attacks the worst of which was in 2000 when he was hospitalised for fourteen days during which the pain did not resolve and he was diagnosed with gastritis. By now he was unwilling to accept that it was gastritis and working in the profession he did enabled him to undertake some investigation into other possible causes. He also contacted some doctors he knew personally and they offered that it was unlikely gastritis would cause the severe symptoms he had experienced. He tentatively self-diagnosed but it was not confirmed until he had set up an appointment with a gastroenterologist at another hospital where he asked that they specifically look for chronic pancreatitis. Initially he hoped it was acute pancreatitis. However CT and ultrasound scans confirmed calcifications in the pancreas and a diagnosis of chronic pancreatitis was made. He feels the delay in diagnosis may have contributed to the development of chronic pancreatitis as he continued to drink alcohol in the intervening six months.

A feels that alcohol probably caused his pancreatitis as in the 3-4 years prior to being diagnosed he drank in the region of one or two bottles of wine per day. However, he feels it may not be the only factor since there was a history of pancreatic problems in his family.

1.2.2 Living with chronic pancreatitis

For **A** everyday living with chronic pancreatitis is about coming to know the pain, knowing its patterns, knowing when it can be managed without help and knowing when to seek help.

Although the nature of **A**'s pain is difficult for him to articulate he describes it as distinctive and cannot be compared to any other pain. It is immediately recognisable yet varies considerably in its intensity and duration. **A** determines that the pain can be largely differentiated between the pain of an acute attack and the everyday low to mid level pain. Everyday low to mid level pain can be endured through constant medication. The nature of the pain is changing as his condition progresses with less acute episodes and more of the constant pain. Sourcing his gastroenterologist and a pain team are help seeking strategies for effective pain management. Trial and error with analgesics, ineffective pain control, possible opiate addiction and side-effects of drugs are acceptable consequences for him if a pain free state could be achieved.

A change in the intensity of the pain is the beginning of a process of determining whether or not to seek help. It involves adjusting and/or increasing frequency of prescribed medication. **A** has several types of analgesia which he juggles in his attempts to managing worsening pain. During this time, he also stops eating and suspends his normal activities. Even if these strategies do not impact on the pain, he will wait for some time, often days, before seeking help. This is in the knowledge that the nature of the pain means it may settle. He is reluctant even when he is experiencing extreme pain to seek help. He says justification for seeking help is found in the reaction of his friends and family to his evident pain and suffering.

Seeking help is accessing hospital services through accident and emergency. He attends the hospital when all self-management strategies have, in his estimation, been exhausted. Attending A&E is a 'triage battle' he is reluctant to get involved in when his pain is incapacitating. Yet, choosing to seek help is mediated by the knowledge that an acute attack can cause multiple organ failure and death.

He sees waiting for long periods of time for attention and treatment in the accident and emergency department as part of the process of seeking help. Maintaining his private health insurance is a strategy he perceives has been successful in enabling him secure a hospital bed on some occasions.

He describes living with chronic pancreatitis as living with a negative label associated with the perception of a self-inflicted condition borne of alcohol dependence. Acute exacerbation of chronic pancreatitis is seen by others as self-induced and is met with the conviction that he must have consumed alcohol. Not being believed about alcohol abstinence is a frustrating feature of interactions with health professionals. Communicating with health professionals is mediated by their attitude to the perceived cause of chronic pancreatitis. **A** believes negative attitudes about chronic pancreatitis impact on the quality of care he receives from some health professionals. He gives the example of being perceived as an addictive personality whose reason for

attending the accident and emergency department was to obtain opiates to which it was assumed he was addicted.

For **A**, weight loss, inability to eat, limited eating, monitoring eating and taking enzyme replacement therapy are all part of everyday living with chronic pancreatitis. Learning about what foods to eat and avoid is an experiential process where the impact is judged by the onset or presence of pain and/or the presence of steatorrhea. Attending to and monitoring dietary intake and weight is a conscious and deliberate process. He describes how he takes some herbal substances as a strategy that he hopes might help.

A describes how he is unable to sleep in a conventional way. Sleep only comes with complete exhaustion. He finds sleep disturbances very debilitating particularly when his pain is at a level where it either prevents him from going to sleep or wakes him up if he is asleep. He strives to find a balance between a level of pain medication that does not incapacitate his daily functioning with achieving a level of sleep that combats exhaustion. Exhaustion reduces his ability to fight the pain.

He describes a life without alcohol as easy. He has a close network of family and friends who understand and respect his need for an alcohol free life. Because of this, he believes he now has a good social life. However, this has been a process of adjustment for him and his friends. He appreciates that it is difficult for others to understand his condition and is compounded by the 'invisibility' of the condition. He is reluctant to discuss it with others as he determines he does not know how to gauge the level of information. He is regarded as 'unusual' in not drinking alcohol in a country where all social life has an alcohol base. Although he recognises that this was 'tricky' at times in the past, he has adapted and manages his social situations so that if he feels uncomfortable or 'bored' he absents himself.

His physical condition and pain interferes with his social life, which frustrates him. At times he isolates himself from friends, ignores calls and invitations and becomes a 'hermit'. This is a coping strategy that he recognises is not ideal but enables him to withdraw and not have to deal with everyday life.

The unpredictability of the condition means he has been unable to commit himself to full-time work. He considers the demands associated with the need to travel, respond at short notice to requirements and tight deadlines are now outside his perceived physical ability. He has wound down his own business and at most undertakes some project work. Following initial rejection and subsequent appeal, he now receives disability allowance.

When the pain is manageable and he is sleeping, he is in a good mood and enthusiastic about making plans for work projects. But the pain returns again sometime later, be it a day or a week and all the plans are deemed over ambitious or ridiculous and have to be shelved. The pain affects his mood and he describes the mental impact as an up and down treadmill. He likens the constant re-appraisal and starting again to the 'Myth of Sisyphus'. **A** feels adjusting to living with chronic pancreatitis has involved lowering his expectations and limiting his goals. It is about coming to accept that he cannot do what he did when he was healthy.

1.2.3 The future

Several factors impact on **A's** thoughts about his future and overall, he does not consider long-term plans whilst living day to day.

Primarily he is uncertain about his prognosis and he cites reluctance by his doctors to discuss it, as frustrating. He feels let down as he has not been informed of his potential prognosis in terms of how his condition will develop or his life expectancy. He does not know how his condition has progressed in six years yet he assumes there has been some deterioration. Equally, he says he tries not think about it too much as he finds it depressing. Chronic pancreatitis he believes is a pessimistic condition with no good news on the horizon.

Because of this he considers it impossible to make long term career or family plans. He would not contemplate getting married or having children if his life expectancy was only 10-15 years as he feels it would be irresponsible. He also feels the unpredictability of his condition from day to day would impact on a relationship with a partner. He feels it would be unfair to impose those restrictions socially and financially on another.

He describes his financial position as untenable in that his income is limited to his disability benefit. In addition he is unable to obtain life insurance due to his condition and, by default, cannot obtain a mortgage.

2.0 Story 2

2.1 Interviews and Reflection

F and I met four times, the first being for the purpose of discussing the study and gaining consent should she be willing to participate. All three interviews were conducted at her home. The interviews took place over a period of four months. The total time of formal recording was 4 hours and 24 minutes.

F was the first woman to come into the study and I began to wonder how her story might differ from that of the men that had preceded her. When arranging our first meeting she told me she could only participate if I was willing to come to her home as she not well enough to go out. I questioned whether she was well enough to talk with me and she indicated that she was 'looking forward to it'.

The formal interviews with **F** corresponded with the pattern established with other participants. The first meeting was contextual where she told me how she came to be diagnosed with chronic pancreatitis. In the second interview we focussed on what had happened in the intervening time since our first meeting although much of the second interview was also about trying to marry aspects of the first interview with what was being said in the second. At times, I had difficulty gaining a sense of her story and what was happening to her. On reflection I believe that **F** had little information and insight into her multiple pathologies and in a sense was able only to relay her own understanding. That this was sometimes incorrect or misinformed intensified my uncertainty, which was evidenced by me often seeming to revisit or check issues that had been discussed previously. Between the second and third interview **F** was hospitalised. She informed me by text message and I went to visit her informally whilst she was there. I sensed that she would appreciate the gesture. Our final dialogue concentrated largely on her hospitalisation and progress since. By the end of the interview she felt she had little new to add and I felt we had achieved successful closure.

My initial impression was that **F** wanted to discuss her experiences as she had not had previous opportunities to do so. She stated how much she looked forward to our conversations as she could talk to me about her condition, something she felt she could not do with others. She was also seeking information and at times asked my opinion. Despite feeling uncomfortable with some of the questions, where possible I answered honestly and objectively and I provided her with the printed information I had given to others. In addition, due to her lack of knowledge I sometimes found myself correcting her misconceptions or clarifying issues for her. Although I felt some disquiet doing this as it was not part of my role as researcher, I felt it would have been unethical not to do so particularly as it simply constituted a verbal reinforcement of the printed information I had given her.

2.2 F's story

2.2.1 The beginning

F is in her 50s and was told she had been definitively diagnosed with chronic pancreatitis 4/5 months previously. She had been experiencing gastrointestinal discomfort and pain for three/four years but following

investigation a year previously she was diagnosed with gastric ulcers and a hiatus hernia. In November, whilst out shopping she experienced an acute episode of pain and vomiting and was subsequently admitted to hospital by ambulance. She describes the pain as 'unmerciful' where she could not walk. She felt the pain was similar to that which she had been experiencing and attributed it to the ulcers or hernia. However, on admission she was informed it was pancreatitis possibly caused by a gallstone obstruction. She was unaware that she had gallstones and although she says she had heard of the pancreas she had never heard of pancreatitis or that it could be caused in this way.

She remembers little of the first two days in hospital and she was consumed by a pain that she will never forget. She was hospitalised for two and a half weeks, during which time she had a laparoscopic cholecystectomy following which she recovered well.

She was readmitted to hospital 2/3 months later with a further attack of pain and at this point she was informed she had chronic pancreatitis and that her case was serious. She has two further admissions since.

2.2.2 Living with chronic pancreatitis

For **F** living with chronic pancreatitis has been a process of trying to come to terms with the additional impositions on her freedom and independence. She finds it difficult to be confined by the physical effects of chronic pancreatitis and sometimes gets angry and frustrated. **F** describes herself as a 'fighter' who has had to contend with multiple illness experiences over her lifetime. Although she has always had a level of dependence on others, because of her compromised vision she is fiercely independent and has managed to live a full life. However she thinks chronic pancreatitis has taken her whole life. Not only is she more dependent on others she feels she has a co-dependency on tablets to get her through the day. She despairs of not being able to go shopping with her daughter or accompany her grandchildren for days out as she used to. Even during periods when she is feeling better a day excursion has the effect of exhausting her. Much of the time though she feels she just needs 'to get on with it'. Even at the end of a bad day she thanks 'Our Lady' for getting her through the day. She says her experiences have increased her faith although she would not describe herself as 'overly religious'.

She describes her husband and children as being very supportive in helping her to meet her day to day needs. However, **F** has not discussed her condition or how she feels emotionally with them. She says her children have been through tough times and she does not want to burden them further. Her husband encourages and facilitates her rest but has not expressed a desire to understand the emotional and psychological impact on **F** or how he feels himself. Nonetheless, she feels her experiences have brought them closer although physical intimacy is no longer possible. **F** recognises that this must be difficult for her husband and she appreciates his understanding.

She has a close friend who lives nearby and they see each other every day. However, **F** feels there is no-one outside healthcare professionals with whom she can discuss her condition. She says people do not know what chronic

pancreatitis is and therefore would not be able to understand what it means for her.

Pain and physical exhaustion are the major factors that impinge on her desire to return to her normal life and 'be well again'. She describes the pain as constant although it varies in its intensity and at its worse is in the region of 7 or 8 out of 10. She has difficulty pinpointing its source and is not sure sometimes whether it is being caused by the hiatus hernia or the pancreas. She experiences pain in her central abdomen but also tells of how it can be on her left side nearer her back. She thought at one time that this pain might have indicated something in relation to her kidneys as she was unaware of the location of her pancreas.

Referral to the pain team resulted in an unsuccessful attempt to control the pain using a 'block'. Therefore, opiate and non-opiate analgesics are the mainstay of her pain management. Generally she adheres to the prescriptions of the former but has adjusted the prescription of the latter to what she perceives is a better regime for her. When the pain is debilitating she either rests completely or tries to distract herself from it by undertaking undemanding tasks.

She finds changes and adjustments to her prescription confusing and cites the differing instructions from the hospital, her GP and pharmacist as unhelpful in facilitating her understanding of the medication.

Uncontrolled or unmanageable pain is a trigger for seeking professional help. Accessing help is either through her GP or through the A&E department. She tries to avoid being admitted to her local hospital and where possible presents at the A&E department of Hospital B. Despite her preference she finds waiting to be seen and subsequent waiting on a trolley for admission to the ward difficult. She describes the environment as stressful, which she says exacerbates her pain and believes the lack of facilities and privacy in the A&E department is degrading.

She perceives her physical exhaustion to be an effect of the opiate medication. She finds undertaking her normal tasks and activities in the house wearing and has to intersperse them with frequent rests. She describes how her muscles are sore and she aches everywhere and wonders whether this is related to her diabetes. She is reluctant to go out as she finds it too tiring and is fearful of an acute attack.

She says she often falls asleep in a chair during the day and when she does so she goes into a 'coma'. The rapidity with which she fall asleep and the depth of the sleep concerns her and she no longer smokes cigarettes when she is alone. By early evening she is often tired enough to go to bed for the night. She takes amitryptiline at night, which she says is not a sleeping tablet but another painkiller to supplement her morphine sulphate. Although she feels she does sleep at night she says the pain may still wake her. If she wakes in the morning in pain and it does not subside following medication she knows she will have a 'bad day'.

Having disrupted eating has become part of **F's** everyday living. She finds it difficult to know what to eat as she thinks foods that are recommended for good diabetes control exacerbate symptoms of her hiatus hernia and vice versa. She no longer eats regular meals as she can only tolerate small amounts of food. On occasion, eating results in the onset of pain thereby reducing her intake further. She attempts to eat snacks every two hours and feels better when she does but her appetite is generally poor. Although she is aware they are designed for digestion she does not always take her pancreatic enzyme replacements prior to eating. She says she felt it was best to take them as they were administered whilst in hospital. She has lost a significant amount of weight but thinks this may be rectified if she adheres to the premise of eating little and often. **F** judges that she has been unwilling to accept the onset of her diabetes. She does not know why this was the case but because of it she determines she has not been managing her diet properly. She believes that adhering to the advice given to her by the dietician has resulted in her beginning to feel better.

F acknowledges that continued interaction with healthcare professionals is part of her living with chronic pancreatitis although she says she is 'tired' of tests and procedures. Even though she is unable to articulate why she 'dislikes' her local hospital, she is happier being treated in Hospital B. She finds the staff supportive and concerned for her welfare but she cannot recall being given information or education on managing certain aspects of her condition. She says she has not been told the extent of the damage to her pancreas though one doctor did tell her she did not realise how sick she was. Nonetheless she has faith in and believes that those responsible for her care are acting in her best interests.

F acknowledges that she sometimes questions why she got chronic pancreatitis. She recognises an element of 'self-blame' stating she must have done something wrong but she does not know why she feels this.

2.2.3 The future

F is unsure if she is coping with living with chronic pancreatitis. She worries that her condition will not improve. Although stoic about accepting the 'bad days' she would be distressed if the level of pain, tiredness and dependence was to be her life permanently. She feels she would accept a 'normal' where she was not 100% but where the symptoms were manageable and allowed her to live how she chose.

3.0 Story 3

3.1 Interviews and Reflection

H and I met three times over a period of three months. Our introductory meeting and first formal interview were undertaken simultaneously as I had to travel a considerable distance to meet with him. All three formal interviews were conducted at his home. The total time of formal recording was 3 hours and 19 minutes.

The first interview concentrated on discussing how and why he had come to be diagnosed with chronic pancreatitis and the impact it has had on his life. Our second interview necessitated little clarification as **H** was happy with what we had discussed in the first interview. The focus therefore, was on revisiting and developing issues that had arisen previously as well as exploring how he had been. Our final interview focussed largely on questions I had arising from the transcript of the second interview. At the end of that interview, we appeared to have achieved a natural closure.

H's wife was present in the house for first two interviews. Both of them made me feel very welcome and I was plied with tea and sandwiches throughout. Although I suggested to **H's** wife that she was welcome to be involved, she declined as it appeared she was anxious about being recorded. However, we did engage in social 'chat' before and after the formal interviews.

During our first interview I was conscious that **H** spoke quietly and had a strong accent, with a smattering of colloquialisms I did not always understand. I was conscious this would impact on transcription therefore I concentrated more intensely on what he was saying in order to minimise asking him to repeat what he had said or having gaps in the transcription. He also had a speaking pattern where when asked a question or after making a point he paused before speaking. Initially I noticed I tried to fill the 'gaps' by expanding my questions or offering explanations. I do not know how I came to know this pattern but when I did I deliberately waited a little longer before speaking.

H was the first participant in the study who said he still drank alcohol and seemed unperturbed about discussing it. Reflecting on why I considered this significant led me to conclude that **H** challenged my developing horizon, borne of my experiences with previous participants that those who continued to consume alcohol would either not volunteer to participate in the study or even if they did would not admit to alcohol consumption. Ultimately this experience broadened my horizon of understanding since it opened the possibilities of gaining some insight into why he made the decision to drink alcohol.

Our dialogues raised some questions about issues I explored with some participants and did not with others. For example, I did not ask **H** to attempt to bring together his articulation of what it was like to live with chronic pancreatitis. On reflection, I felt this was bound in my perceived ability to interpret his living. With some participants I had a sense of unease associated with the interpretation of meaning resting with me, whilst with others it appeared less threatening. I concluded this was bound in how well I felt I had understood 'their story'.

3.2 H's story

3.2.1 The beginning

H is in his 50s and was diagnosed with pancreatitis three years previously. He says he could be described as an alcoholic and he has attended detoxification programmes four times none of which he has completed. He continues to drink alcohol although the volume is much less than it used to be.

H's first attack of pancreatitis occurred at work where the onset was sudden and severe. The pain was so bad he started to become disorientated and confused. With the help of his brother he went to his GP who gave him an injection after which the pain settled. He thought he had ulcers. He was drinking heavily at the time and two weeks later he got another acute attack of pain. He was sent to his local hospital where it was found his amylase was very high. He was informed he had pancreatitis and was told to stop drinking alcohol. Although he claims he was not frightened by the diagnosis, the pain was so severe he stopped consuming alcohol for the next three months.

After a time he began to feel better and began to drink alcohol again with the result that he was hospitalised in the region of eight times over a period of two years. The length of time between commencing alcohol consumption and the onset of pain decreased each time. Finally, following an MRI scan a build up of fluid in the pancreas was noticed and he was referred to the consultant under whose care he remains. He had exploratory surgery in where a tube was inserted from his 'pancreas to his bowel'. He has had two further hospitalisations since with pain induced by a 'blocked bile duct'. Attempts at endoscopy have been unsuccessful.

He was familiar with pancreatitis since both his brother and brother-in-law have been diagnosed with acute pancreatitis. Following his only acute episode, his brother abstained permanently from alcohol. However his brother-in-law did not stop consuming alcohol and subsequently died following an acute attack.

3.2.2 Living with chronic pancreatitis

For **H** living with chronic pancreatitis is being constrained in his ability to live his life as he would wish. He is no longer able to work and cannot socialise in the way he has since he was a young man.

A life without alcohol is not possible for **H**. For him, the extreme change from drinking alcohol as a way of life to one without alcohol cannot be contemplated. Knowing others who have been incapacitated or died from alcohol induced pathologies does not prevent him from consuming alcohol. Nevertheless, he does think that he is 'paying for' years of heavy drinking and that he 'got away with it' for a long time. Although fear of the pain mediates his alcohol consumption and the volume and frequency of his drinking is significantly reduced he says he will always take a 'gamble'. He describes his episodes of drinking as 'occasional', where he consumes in the region of five or six pints, which to him is 'not much'.

He has been offered and availed of professional help to stop drinking alcohol. However, each time he has had more pressing priorities and did not complete any of the programmes. Moreover, he believes he has never hit 'rock-bottom' and has always discharged his responsibilities. However, he does continue to take medication, which he says is designed to 'stop him drinking'. He has also resisted attempts to persuade him to stop smoking cigarettes even though he realises his respiratory problems are related to his habit.

Informally, he says his brother 'watches' him and tries to persuade him to adapt his behaviour in order to stay 'well'. His wife tends to become angry when he is drinking and challenges him by suggesting she will not support him if he becomes unwell. However, he says, her responses are similar to those in the past when she considered he has been consuming too much alcohol. At times, this has led to arguments between them and he feels some regret at some of the things he has said and what she has had to endure. He thinks she becomes anxious and stressed each time he experiences an acute exacerbation of his condition. He believes he is not the same man he used to be in that he was happier and more fun when he felt able to drink alcohol. He thinks he is more morose and bad-tempered now.

H thinks he cannot socialise without alcohol and in formal social situations he will always plan to do so. Generally, however, he precludes himself from day to day informal socialising in the pub as he says he will not go there and drink non-alcoholic drink. As a result he feels time drags and he becomes 'fed up'. He sometimes feels resentful of his family's freedom to drink alcohol and their ability to enjoy themselves whilst he stays at home

Being unable to work exacerbates his sense of time 'dragging'. He spends some time each morning with his brother but apart from that and reading the newspaper he has little else to occupy him. He has undertaken some creative projects in the past but has little motivation to complete them. He says such is his perceived lack of motivation that he constantly procrastinates even on necessary tasks. Physically, he experiences back and shoulder pain, which he believes prevents him from partaking in hobbies outside the home. In addition, he thinks his breathlessness is getting 'worse' so much so that he cannot walk any distance. However, he enjoys music as it helps him to relax.

He considers he is too young to be unable to work but he can no longer meet the physical demands of his occupation. Having worked all his life in one job, he recognises he does not have skills to transfer to less demanding employment. He availed of a redundancy package when offered as, being a casual employee, he was not paid when he was not working. Therefore, his numerous hospitalisations and outpatient attendances following the onset of chronic pancreatitis were affecting his income and in his last year of working he was sick for about nine months. As the redundancy package was calculated on income, he feels aggrieved that it was less than it might have been.

Being on disability allowance means that he and his family are financially constrained. He finds trying to understand the system of benefit payments and entitlements baffling and at times resents the impositions that his status has on the family. He finds the social welfare employees unhelpful in this

respect but recognises that in some ways he lacks the motivation to seek the information he needs.

H believes he is more aware of his body now and he draws inferences about his condition from alterations in its functioning. He monitors his urine and faecal output for indications of a possible deterioration in his liver or pancreas or the onset of pain. Changes in his bodily functions frighten him as he anticipates a worsening of his condition.

Monitoring his diet has become part of day to day living although preparation and selection of appropriate foods is undertaken by his wife. He believes he eats more healthily than he used to and tries to avoid foods he considers 'not good for him'. His weight is steady and even if he loses weight in hospital, it resolves when he comes home. He is not a diabetic but his blood sugars have always been 'borderline' but he has not been told to self-monitor these.

Having disturbed sleep is a long term feature of **H's** living. Although he attempts to impose limits on his analgesia and night sedation as he believes they are not 'good' for his stomach, he always has to re-instate them due to poor sleep and poor pain control.

The onset of pain is a marker for **H** to stop drinking alcohol. Since his initial acute attack his body's tolerance for alcohol has decreased and in addition to pain he sometimes develops nausea and vomiting. At these times he also stops eating and drinking until the symptoms settle. Along with his self-imposed suspension of eating and drinking, his primary method of management is analgesia in the form of non-opiate medication. Although he takes analgesia on a day to day basis to control pain, increasing pain necessitates increased medication, the amount of which he judges himself. He describes the pain of pancreatitis as the worst he has ever experienced. He says it defies description but is immediately identifiable and 'shoots out through his back'. At times it was so severe he felt he would rather die than tolerate it.

Inability to tolerate the pain is a trigger for seeking help mainly through his GP who subsequently determines whether hospitalisation is required. Seeking help out of hours is challenging as he says doctors are reluctant to visit the home. In addition, being transported to hospital via ambulance is unendurable as it tends to exacerbate the pain and where possible he avoids it. In order to avoid these acute episodes and such is his fear of the pain his help-seeking behaviour has changed. He no longer delays seeking help but consults his GP at the first indication of worsening pain.

Being hospitalised and outpatient attendance is part of **H's** living with chronic pancreatitis. He alternates between Hospital A and Hospital B where the former is often the first point of admission. However, since his referral to the consultant in Hospital B he is often transferred. Although he feels he is lucky to have been referred to Hospital B, he dislikes being hospitalised so far from home for up to periods of two weeks. His family are unable to visit without incurring considerable expense. Therefore he spends much of his time alone.

Although **H** believes hospitalisation is a necessary part of his living, he has developed strategies for manipulating what he sees as the shortcomings of the system in respect of managing his pain. He believes analgesia in hospital is not adequate and supplements it with his own, a practice he conceals from hospital staff.

Outpatient attendance is required at both hospitals although he is not always sure of why he is seeing the various consultants. Attendance at Hospital B is demanding and often, he claims, dissatisfying if he is unable to be seen by the consultant whose opinion and expertise he values.

3.2.3 The future

H is not happy with his life as it is now yet he cannot envisage it changing for the better. He says everyday is the same and he has nowhere to go and nothing to do.

4.0 Story 4

4.1 Interview and Reflection

During our second meeting **D** indicated that his mother would be happy to talk to me about his parents' living with his chronic pancreatitis. We made contact and subsequently undertook the interview by telephone.

D's mother offered further context for his story. She offered her perspective of what he was like as a child and an adult growing up with an exceptional talent.

The interview with **D's** mother added another perspective to his story. I felt I understood what it was like for her watching her son suffer with this condition. Fundamental to this understanding was my own sense of being a mother. Previously I believed my understanding of living with chronic pancreatitis was bound in my conception of what it meant to be a nurse. For the first time I experienced the practical application of Heidegger's and Gadamer's notions that Being (*Dasein*) as a being of understanding implies an element of self-understanding in that it is always a possibility of my own self that is played out in understanding. It is **I** who understood **D's** mother but only to a certain extent.

4.2 **D's** mother's (P) story

Living with her son's chronic pancreatitis is described by **P** as 'awful'. She describes the family's initial shock when told **D's** amylase reading was 12 times the normal. As a healthcare professional she knew of people with such readings who were in intensive care and felt it was lucky that **D** did not die during an acute attack. She acknowledged that part of their shock was bound in their previously held view that chronic pancreatitis was associated with chronic alcoholism.

She finds the lack of a definitive diagnosis and waiting for tests and results exasperating. Equally, she cannot understand how the tests he had done are not showing organic damage given that he is suffering so much on a daily basis. Although overall she determines the system in Ireland is no worse than in her home country, she feels a true picture of **D's** illness experience has not been possible as a report concerning his amylase has been 'lost'. She also believes the stereotypical view of the person with chronic pancreatitis with a self-inflicted condition may impact on the information that is made available. For example, she finds it disconcerting that **D** was prescribed pancreatic enzyme replacement therapy but was never informed if he should continue them.

Although initially **P** and her husband insisted on **D** having a consultation and tests in their own country, they have not pursued it further as they are aware that his consultant in Ireland specialises in the area. Nevertheless, she feels it has been a very slow process and if his situation is not clarified in the near future then his decision to defer his academic programme for a year will have been in vain.

She acknowledges her 'wish' to have **D** at home in order that they can facilitate the best possible care for him. However **P** and her husband accept

there is need for balance between their concern for **D's** welfare and his right to make autonomous decisions about where his care takes place. She believes, however, he needs to get his healthcare professionals to 'listen'. She feels he is not giving them insight into his everyday suffering, which she finds frustrating. She does not understand why in consultations he does not explain fully the impact of how he is feeling and only offers answers to what is asked. Nor does she comprehend why he has not gone to hospital when he is acutely unwell. To this end she persuaded him to seek help during his current phase of feeling ill.

P struggles to come to terms with what has happened to **D**. She has spent some time thinking about why it could have happened. She knows he drank alcohol on a regular basis and that on some occasions he would 'binge' drink with his friends. However she says she never saw him 'incapable' because of alcohol. She thinks the fact that **D** has had a number of allergies during his life might have some bearing although health professionals have dismissed these views as irrelevant referring only to the significance of alcohol.

She finds it 'absolutely awful' to watch him struggle to eat particularly as he used to love food. She tells of how he adopts strategies to facilitate eating but that he no longer enjoys it and he does so only to stay alive and not get too thin. Being invited out for a meal is difficult for **D** as he cannot or will not eat most things.

Since the onset of his illness **P** sees **D's** lack of confidence around other young people and she sees it as significant in terms of getting a girlfriend. She says he does not fit in and is old before his time. She maintains it is hurtful for a young person such as **D** not to be able to go out and have fun. He rarely goes out to the pub as he conceives himself as 'boring'. Even if he does venture out, he has been berated for not drinking and has been described as a bore with the rider that 'one drink won't kill you'. **P** argues societal emphasis on drinking alcohol to enjoy oneself isolates **D**.

P describes **D** as a very determined young man and when he was told never to drink alcohol again, he abstained immediately and has not drunk since. Therefore she finds it difficult when he is not believed about his alcohol consumption. She says he believes he is giving his body the best chance. Despite this he continues to suffer and remains in pain.

Appendix 9: Examples of early Tree and Free Nodes

Tree Nodes

Being in pain
Being 'normal'
Being 'restricted'
Coming to know
Decision-making
Family members 'living' with chronic pancreatitis
Interacting with healthcare professionals
Managing pain
Salient physiological disruption
Seeking Help
Support
Using the healthcare system

Free Nodes

Accepting limitations
Adjusting expectations
Avoidance
Bad Days
Balancing risk-reward
Behaviour in illness
Being afraid
Being angry
Being informed
Changing challenges
Coming to know
Conflicting information
Confounding symptoms
Control
Coping
Defining 'me'
Disclosing
Disconnected norms
Disordered memories
Disruptive hospitalisation
Distraction
Effect of medication
Embodied 'now'
Embodied past
Emotional connectedness
Empathising with your healthy self
Enduring restrictions
Enforced change
Environmental constraints
Fear of complications
Fear of future
Feeling alone
Feeling better
Feeling valued
Financial implications
Good days
Hopes
Life before chronic pancreatitis
Limits of suffering
Listening to my body
Loss of confidence
Managing consequences
Managing limitations
Medication
Mental strength
Monitoring
'New normal'
Non-positive action
Over-coming 'it'
Paralleling
Passing time
Perceived consequences of non-compliance
Personal Relationships
Personal Values
Physical vulnerability
Psychological vulnerability
Recognising need for change
Retribution
Seeking balance
Self-agency
Social Influences
Social Interaction
Social Isolation
Social Milieu
Spirituality
Taken-for-grantedness
Taking positive action
Trading
Transforming experience
Unacceptable Losses
Uncertain Body
Uncertain future
Unknowing
Unknowing self-damage
Unpredictable 'norm'
Unsustainable 'old' normal
Validating
Verifying to others
Waiting
What if

**Appendix 10: Feedback from School of Nursing & Midwifery Ethics
Advisory Committee**

Ethical Review Sheet

(From Operational Procedures for REC Guidance, p.16-18,
Irish Council for Bioethics, 2004)

Proposal Review Sheet

Proposal No.90/05 Review Date 15th June 2005 By _____

Area	Section	Comments/Concern
Scientific design & conduct		
Recruitment		
Care & protection of subjects		Please consider having a time lapse between the interviews and getting written consent. Some concern was expressed about the researcher's safety while interviewing in the home.
Protection of confidentiality		
Informed consent process		No. 10 on the information sheet needs to be changed. Please put in the first line of the information sheet that you are a nurse. Please make the possibility of interviews with family members explicit. Therefore, you need to develop a consent form for families.
Community considerations		

Appendix 11: School of Nursing & Midwifery Ethics Advisory Committee permission to proceed to Ethics approval

From: Virginia Dunn [dunnv@tcd.ie]
Sent: 24 June 2005 13:41
To: 'Patricia Cronin'
Subject: RE: Response to Ethics review 15.06.05

Great Trish. In the Family Information Sheet, in Section 4, the last sentence of the first paragraph is redundant with what follows in the next paragraph. Other than that editorial comment, the family member's information sheet, consent form and general consent form is in line with our concerns. We wish you well with the study.
Ginny

-----Original Message-----

From: Patricia Cronin [mailto:pcronin@tcd.ie]
Sent: 24 June 2005 13:16
To: 'Virginia Dunn'
Subject: Response to Ethics review 15.06.05

Dear Ginny

Please find attached my responses to the comments/concerns made at the School of Nursing & Midwifery Ethics Committee meeting on the 15th June in respect of my PhD research proposal.

If you have any further queries or if I have forgotten anything or if I have not responded appropriately please do not hesitate to contact me.

Thank you

Tricia

Lecturer in Nursing
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