

Where is the Person in Symptom Cluster Research?

The Experience of Symptom Clusters in Patients
with Advanced Lung Cancer

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Thesis submitted for the Degree of Doctor of
Philosophy

August 2011

Table of contents

Table of contents.....	I
List of Tables.....	V
Abstract.....	VI
Acknowledgements	X
Declaration.....	XII
Chapter 1: Introduction	1
1.1 <i>Rationale for thesis</i>	1
1.2 <i>Structure of thesis</i>	8
Chapter 2: The illness experience.....	13
2.1 <i>Introduction</i>	13
2.2 <i>Illness or disease?</i>	13
2.3 <i>The biomedical model</i>	17
2.3.1 <i>Benefits of the biomedical model</i>	18
2.3.2 <i>Critique of the biomedical model</i>	21
Chapter 3: The study of symptom clusters in patients with cancer	42
3.1 <i>Introduction</i>	42
3.2 <i>The definition of a symptom</i>	43
3.3 <i>Conceptual frameworks of symptom clusters</i>	48
3.4 <i>Empirical studies of symptom clusters in patients with cancer</i>	58
Chapter 4 Methodology	70
4.1 <i>More than a method</i>	72
4.2 <i>My epistemological position</i>	77
4.3 <i>Qualitative research methodologies</i>	79
4.4 <i>Rationale for using IPA</i>	91
Chapter 5 Study methods	94
5.1 <i>Introduction</i>	94
5.2 <i>Aim of the study</i>	94
5.3 <i>Study design</i>	95
5.4 <i>Patient population</i>	95
5.4.1 <i>Clinical site</i>	95
5.4.2 <i>Sampling strategy and sample size</i>	96

5.4.3	Selection of the sample.....	97
5.4.4	Process of recruitment.....	100
5.4.5	Ethical considerations	101
5.5	<i>Data Collection</i>	106
5.5.1	Semi-structured or unstructured interviews?.....	107
5.5.2	Details of interviews	109
5.6	<i>Data Analysis</i>	114
5.6.1	Reading and re-reading of the interview transcripts	115
5.6.2	Initial noting	116
5.6.3	Looking for themes in the first case.....	119
5.7	<i>Reflexivity</i>	127
5.8	<i>Assessing validity</i>	128
5.8.1	Sensitivity to context	128
5.8.2	Commitment and rigour	129
5.8.3	Transparency and coherence.....	129
5.8.4	Impact and importance.....	130
Chapter 6	Pilot Study	131
6.1	<i>Introduction</i>	131
6.2	<i>Conduct of the pilot study</i>	132
6.2.1	Population.....	132
6.2.2	Recruitment process and study sample	134
6.2.3	Interviews	136
6.2.4	Data analysis	144
6.2.5	Conclusions drawn from the conduct of the pilot study.....	146
Chapter 7	Introduction to the results chapters	148
7.1	<i>Summary of study results</i>	148
7.2	<i>Study Population</i>	159
7.3	<i>Details of interviews</i>	164
Chapter 8	The lived experience of symptom clusters and the role of context and meaning	165
8.1	<i>The experience of symptom clusters</i>	166
8.1.1	Identifying 'salient' symptoms	177

8.2	<i>Death</i>	182
8.2.1	The meaning of lung cancer - death.....	184
8.2.2	Fear of death and the experience of symptom clusters	186
8.2.3	Fear of death and coping with symptom clusters.....	195
8.3	<i>Stigma</i>	199
8.3.1	Childhood recollections of stigma.....	200
8.3.2	Lung cancer: A self-inflicted illness?	202
8.3.3	Stigma and the lived experience of symptom clusters	207
8.4	<i>Conclusion</i>	217
Chapter 9	Symptom clusters and loss of sense of self	221
9.1	<i>Introduction</i>	221
9.2	<i>The Impact of Symptom Clusters on the Self</i>	222
9.3	<i>Being a burden</i>	238
9.4	<i>Trying to maintain a coherent and valued self</i>	243
9.4.1	Comparing themselves to other people with cancer	243
9.4.2	Normality	248
9.5	<i>Conclusion</i>	253
Chapter 10	Discussion.....	256
10.1	<i>Introduction</i>	256
10.2	<i>Strengths and limitations of this study</i>	257
10.3	<i>Discussion of study findings with wider reference to the wider literature</i>	272
10.3.1	Summary of key findings	274
10.3.2	Study findings with reference to the wider literature	276
10.3.3	The patient experience and current definitions.....	277
10.3.4	The patient experience and current empirical base	286
10.4	<i>Conclusions and Recommendations</i>	295
10.5	<i>Recommendations for research</i>	299
10.6	<i>Recommendations for clinical practice</i>	301
References	306
Appendices		342
	<i>Appendix 1: Patient Information Sheet</i>	342
	<i>Appendix 2: Consent to pass on personal details</i>	346

<i>Appendix 3: Patient consent form</i>	347
<i>Appendix 4: Interview summary/reflexive notes</i>	349
<i>Appendix 5: Examples of empirical studies of symptom clusters in patients with cancer (2001-2011)</i>	350
<i>Appendix 6: Example of analysed transcript</i>	380

List of Tables

Table	Title	Page Number
Table 1	Databases used for literature search according to topic and keywords	9
Table 2	Assumptions of the biomedical model	17
Table 3	Theories and model underpinning the study of symptom clusters in patients with cancer	50
Table 4	Definitions of symptom clusters in patients with cancer	54
Table 5	Details of inclusion and exclusion criteria	99
Table 6	Initial noting	117
Table 7	Looking for themes in the first case	120
Table 8	Super-ordinate theme 'Fear of Death' and related Sub-themes	123
Table 9	Super-ordinate themes for Dan	124
Table 10	Identifying recurrent themes	126
Table 11	Demographic characteristics of the pilot phase sample	133
Table 12	Super-ordinate themes, sub-themes and themes derived from this study	150
Table 13	Characteristics of participants recruited	160
Table 14	Symptom clusters identified from participants' narratives during interviews	169
Table 15	Framework for clinical practice for the management of symptom clusters in patients with advanced lung cancer	304

Abstract

Where is the Person in Symptom Cluster Research? The Experience of Symptom Clusters in Patients with Advanced Lung Cancer

This thesis describes a three-year qualitative study which aimed to explore the experience of symptom clusters in patients with advanced lung cancer. The study employed a patient-focused approach utilising Interpretative Phenomenological Analysis (IPA) (Smith et al. 2009a). This methodology (IPA), informed by a contextual constructionist stance, was selected to explore the experience of symptom clusters, for its focus on the lived experience, the context and meanings which surround such experiences and its idiographic approach.

Ten patients (a sample size which is the upper limit of the number of participants advocated for studies employing IPA (Smith et al. 2009b; Reid et al. 2005; Smith and Osborn 2004)) with advanced lung cancer took part in the study and data were collected using unstructured, in-depth interviews at two time points: on recruitment and three to five weeks later. Data were analysed using

Interpretative Phenomenological Analysis, within the framework advocated by Smith and Osborn (2003).

The study generated interesting and significant findings. The experience of symptom clusters in patients with advanced lung cancer was characterised by two super-ordinate themes: 'The lived experience of symptom clusters and the role of context and meaning' and 'Symptom clusters and loss of sense of self'.

The super-ordinate theme of 'The lived experience of symptom clusters and the role of context and meaning' in the first instance, illustrates that the participants in this study were experiencing symptom clusters and providing detail on the components, nature and patterning of the symptom clusters reported, particularly the way that one or two salient symptoms were commonly highlighted from all the other symptoms experienced. This super-ordinate theme also demonstrates the core role that context and meaning play in the lived experience of symptom clusters, with many of the participants in this study framing their experiences of symptom clusters within a fear of death, stigma and loss of sense of self.

The second super-ordinate theme informing this thesis is 'Symptom clusters and loss of sense of self'. This super-ordinate theme illustrates the impact of symptom clusters on the participants' lives, and how this, in turn, impacted on their sense of self in a number of different ways. For some, their sense of self was compromised by the concurrent symptoms that they were experiencing, as they prevented them from undertaking roles and activities that they were accustomed to in the past. This super-ordinate theme also highlights the role of the body relative to the self, and describes how the participants' sense of self was transiently lost during periods when they experienced symptom clusters of high severity. The findings presented also demonstrate the knock-on effect of loss of sense of self experienced, with the participants feeling like they were a burden due to their incapacitation, and at times hiding the multiple symptoms that they were experiencing, in a bid to protect their loved ones from their illness. In light of the loss of sense of self experienced, this super-ordinate theme also demonstrates how the participants employed various strategies in a bid to try and maintain a coherent and valued sense of self.

The findings presented illustrate how the use of IPA facilitated the collection of data that provided an in-depth understanding of the complexity of the experience of symptom clusters in patients with

advanced lung cancer, adding a unique contribution to this body of knowledge.

The results of this study highlight the limitations of definitions that currently underpin the study of symptom clusters in patients with cancer and the current empirical base to date, particularly the way that they do not acknowledge the core role that context and meaning play in the lived experience of this phenomenon. This lack of recognition of these core elements of the patient experience of symptom clusters poses the risk of this body of research producing data that have limited relevance to the patient and therefore clinical practice.

It is therefore proposed that the study of symptom clusters in patients with cancer needs to move away from the reductionist approach which currently dominates and to broaden its scope, to one that acknowledges the complexity of the experience of symptom clusters, the core role that context and meaning play in such experiences, and contributions that patient experience can make in advancing this important and emerging body of research.

Acknowledgements

First and foremost, I would like to thank the patients who have participated in this study and who have been so willing to share their valuable time and personal experiences with me. Their experiences will stay with me forever and will fuel my drive for the 'voice' of the patient to be heard and counted.

I would also like to thank my supervisors Professor Nora Kearney and Dr. Kath Stoddart, for their guidance throughout this PhD, for challenging my self-doubt, for believing in my capabilities and supporting me through the good bits and the bad. This thanks also extends to Professor Paul Flowers from Caledonian University, for his guidance on the methodology selected for this study (IPA), and for his unending patience and dedication which was way beyond the call of duty. I would also like thank my colleagues, who have provided me with endless support and for always being there in my hour of need.

Last but not least, I would like to thank my family. My dear husband Stephen, for his encouragement, support and love, and without

whom, this thesis would not have been possible. To my beautiful daughters Olivia and Julia, who despite being so young offered much support and gave up valuable 'mummy' time to allow me to write this thesis. I hope that this experience will teach them never to give up, to believe in themselves and to follow their dreams. I would also like to thank my mother-in-law Margaret, for providing me with endless support and helping me juggle with the demands of being a mother, holding down a full-time job and at the same time undertaking a PhD. Finally I would like to thank my dear mother Maria, who has always been there for me, offering support, guidance and love.

Declaration

I declare the work in this thesis to be my own, except where otherwise stated.

Roma Maguire

August 2011

Chapter 1: Introduction

1.1 Rationale for thesis

My interest in the concept of symptom clusters and rationale for this thesis started when I was contemplating undertaking a PhD and looking at potential topics in which to base my thesis on. I knew that I wanted to carry out my research in the area of cancer symptom management based on my clinical background and research interests at that time, however, I also wanted to research into an area that was relatively novel but at the same time had the potential to make a positive impact within clinical practice.

I had read an editorial which discussed a relatively new concept of a symptom cluster in patients with cancer. Immediately on reading this editorial, this topic captured my attention, particularly as it was introducing a different approach to symptom management that had not previously been explored and had real potential to make a dramatic change within clinical practice. My enthusiasm was heightened by my previous extensive clinical experience in caring for people with lung cancer.

From my experiences of working with this patient population and with wider reference to the literature, I was aware that lung cancer was one of the commonest forms of cancer (International Agency for Research on Cancer 2000) and that its incidence was increasing in many countries (Ferlay et al. 2007). I was also cognisant of the fact that it was the leading cause of cancer-related deaths in men and women in Europe (International Agency for Research on Cancer 2000), with only 12% of people living 5 years or more, and with this figure being significantly less for people residing in the UK (Sant et al. 2009). Linked to such poor survival figures was also an awareness that most people with lung cancer died within an 8-12 month period of diagnosis (Sola et al. 2004), and that this factor was significantly influenced by the fact that they often presented with advanced disease (Corner et al. 2005). Therefore, based on my clinical practice, I was aware that for most patients, within this short space of time, had to undergo a range of invasive procedures and toxic treatments such as chemotherapy and radiotherapy, whilst at the same time having to deal with supportive and palliative care issues due to both the trajectory of the disease and the side-effects of treatment.

Therefore, it was not surprising that this group of patients commonly experience multiple symptoms (Cleeland 2007; Cooley et al.

2003b;Cooley et al. 2002; Cooley 2000; Sarna and Brecht 1997; Sarna 1993), experience significant distress due to their symptoms (Molassiotis et al. 2010; Cooley et al. 2003b; Cooley et al. 2002; Cooley 2000;Tishelman et al. 2000; Degner and Sloan 1995) and are reported to have a significant number of concerns regarding existential issues (Coyle 2006; Coyle 2004; Weisman and Worden 1977). Therefore, I felt that to conduct research in the area of symptom clusters would be of considerable benefit to patients with lung cancer and had the potential to make a significant contribution to clinical practice in the future.

However, whilst I found the concept of symptom clusters in patients with cancer of significant interest, on reading the literature pertaining to this area of research I was surprised at the lack of scientific evidence informing this concept and the way that symptom clusters were portrayed using statistical associations, which I felt represented little of the underlying reality of the symptom experience which I had witnessed in practice for a number of years. For months I kept thinking that I must be missing some seminal papers, that surely this concept had not been developed and explored without an appreciation of the experiential expert - the patient. However, my endless searches remained futile, leading me to the conclusion that this really was the case, and that to date, no study had formally

explored the patient's perspective of this concept of symptom clusters in the context of their lives. I therefore decided that, in light of the significant limitations identified, I would make a novel contribution of knowledge and conduct a study formally exploring the experience of symptom clusters in patients with cancer from their perspective.

For the purpose of this study, a symptom cluster is defined as being the experience of three or more concurrent symptoms. This definition of symptom clusters used in this thesis is based on existing definitions of symptom clusters in patients with cancer which purport that 'concurrency' is a core characteristic of this phenomenon (Kim et al. 2005; Dodd et al. 2001b) and where the number of symptoms thought to constitute a symptom cluster is three or more (Dodd et al. 2001a; Dodd et al. 2001b). Furthermore, the characteristic of concurrence has been used as evidence of symptom clustering in previously published qualitative studies of symptom clusters in patients with cancer (Lopez et al. 2011; Molassiotis et al. 2010; Molassiotis et al. 2008). In addition, the term symptom cluster used in this thesis includes symptoms which are derived from the toxicities of cancer related treatments. This characteristic of symptom clustering is recognised in existing definitions of symptom clusters, where it is stated that symptoms within a cluster may originate from

different aetiologies (Kim et al. 2005; Dodd et al. 2001b). Furthermore, several papers have been published in the literature which report on treatment related symptom clusters in patients with cancer (Kim et al. 2009; Maliski et al. 2008; Hadi et al. 2008b; Given et al. 2007; Kim et al. 2007; Nail et al. 2006; Francoeur 2005).

I decided that the best way to explore the patient experience of this concept was to use a qualitative approach as discussed in chapter 4 which, instead of trying to reduce the experience to statistical associations, would embrace the experience of symptom clusters in patients with cancer in all its complexity and reality. This choice was based on my epistemological stance and belief that knowledge is influenced by the perceptions of the person in the context of their lives, and that there is not one but many knowledges about any one phenomenon.

Having decided on a qualitative approach I then had to decide on what methodology would be most appropriate to address the aim of my study and the research questions posed. IPA was selected for its affinity with my epistemological stance and its focus on the lived experience and the role of cognitions, which I felt were central to explore and understand the experience of this phenomenon from the

perspective of the patient. Furthermore, in comparison to the other methodological approaches which I considered, IPA paid particular homage to the idiographic experience at the level of the individual, which I felt was extremely important and strengthened the patient-centred approach that I intended to adopt.

Patients with advanced lung cancer were selected for the study sample primarily as they are known to commonly experience multiple concurrent symptoms and have been reported to experience higher levels of symptom severity and distress compared to patients with other cancer types (Cooley 2000). Furthermore, a number of various symptom clusters had already been reported in this patient group in the literature (Wang et al. 2008; Brown et al. 2007; Fox and Lyon 2006; Wang et al. 2006; Gift et al. 2004; Gift et al. 2003). As stated earlier, although secondary to the selection of the study sample, this choice appeared to be fitting in light of this group of patients giving me the original impetus to explore this concept further in patients with advanced lung cancer, and my significant clinical experience of caring for them.

The method of data collection was once again informed by my epistemological stance (contextual constructionist) and a drive to

maintain a patient focus, and to explore the concept as far as possible from the perspective of the patient within the context of their lives. Consistent with IPA, I therefore chose unstructured interviews, as I felt that this approach facilitated the inductive bottom-up generation of data, allowing the participants to talk about issues of importance to them in their lives in the first instance, before focussing upon their experience of symptom clusters. Such an approach facilitated the collection of data which allowed me to elucidate the participants' experiences of symptom clusters within the context of their lives, which I felt was fundamental to me understanding such experiences and therefore addressing the aims and research questions posed in this study.

As will be evident in the following chapters of this thesis, the approach used in this study provides a detailed and realistic understanding of the experience of symptom clusters in patients with advanced lung cancer, making an important contribution to this body of knowledge. Having outlined the rationale and approach used in this thesis, I will now provide a brief summary of the structure of this thesis.

1.2 Structure of thesis

The following two chapters of this thesis (chapters 2 and 3) begin with a review of the literature. The literature in these chapters was identified from various sources, including database searches, PhD theses, conference proceedings and reference lists from key research papers. Key words for literature searching were identified from the study aims and from articles accessed in the early stages of the review and these are displayed in table 1 below. However, whilst using such keywords proved to be successful in identifying the literature pertaining to symptom clusters in patients with cancer, they were of less benefit in identifying seminal works relating to medical anthropology or the sociological study of illness and disease, aspects of which I was aware would form a significant part of review and critique of the literature. Therefore, to substantiate the search of databases detailed in table 1, I also had to identify some seminal works pertaining to such areas (Kleinman 1988b; Cassell 1982; Good and Good 1980; Kleinman 1980; Cassell 1978) and use them as a source of identifying more and recent perspectives on the study of health and illness.

Table 1: Databases used for literature search according to topic and keywords (no date range applied)		
Database	Keywords	Hand-searched journals
CINAHL	Lived Experience	Cancer Nursing
Medline	Experience	Oncology Nursing Forum
PsychInfo	Symptom/s	Journal of Pain and Symptom Management
ASSIA	Side Effect/s	
	Toxicity/Toxicities	
	Symptom Cluster/s	
	Lung Cancer	
	Cancer	

The second chapter of this thesis, 'The Illness Experience', starts by discussing different conceptualisations of the illness experience, highlighting the contrasting assumptions made within each approach. It then highlights how, to date, the biomedical model, with its focus on disease and the physical domains of the illness experience, continues to dominate current health care. Using a critique of the literature, whilst recognising the substantial benefits of the biomedical model to date, I review the multiple challenges made to it over the past four decades. I discuss how many of the challenges made some years ago remain valid today, particularly the limitation of the biomedical model to fully include lay perspectives of illness, its affinity with reductionist methods of measurement and its neglect of

context. This discussion is then followed by an exploration of the alternative models which have been developed in direct response to many of the identified criticisms of the biomedical model. It is argued that these models offer a more humanistic approach to the experience of illness, which go far beyond the physical confines of the biomedical model and therefore may be argued to be more fitting to deal with the complexities of the illness experience.

The third chapter of the thesis continues the critique of a reductionist approach and discusses its dominance in the study of symptom clusters in patients with cancer. It debates how current definitions have employed a biomedical stance, defining symptom clusters in terms of relationships between symptoms, the aetiology of symptoms and the impact of symptoms on patient outcomes. It is argued that the biomedical perspective employed in current definitions has influenced the way that researchers have approached the study of symptom clusters in patients with cancer, with most studies employing quantitative approaches and reductionist methods of measurement. It is argued that whilst such approaches have contributed to the knowledge base of symptom clusters in patients with cancer, the predominant use of quantitative methodology has resulted in a body of evidence which explains the concept of symptom clusters primarily using statistical associations which, it is

contended, reflect a narrow view of the underlying reality of the experience of symptom clusters in the patients' lives. It is therefore postulated that in order to develop and strengthen the concept of symptom clusters in patients with cancer, it is imperative that the patient's perspective of this phenomenon is explored.

The discussion in Chapter 4 follows the arguments made in the literature review chapters and explores the need to understand the patient experience of symptom clusters using an individualised approach and highlights the rationale for adopting a qualitative approach utilising IPA in the current study. Chapter 5 describes in detail the aims, study design, sample recruited to the study, and the rationales for the choice of the particular methods that were employed. The chapter also considers how these data were analysed.

In Chapter 6, the conduct and the findings from the pilot study and the modifications that were made in preparation for the main study are presented. In Chapter 7, the findings of this study are introduced as well as the patient sample, and details of the interviews conducted in this study. In chapters 8 and 9, the study findings are presented, describing the two super-ordinate themes ('The lived experience of

symptom clusters and the role of context and meaning' and 'Symptom clusters and loss of sense of self') identified in this study and the themes that inform these. In Chapter 10, the strengths and limitations of the study are considered and the findings discussed in relation to the wider literature and existing research. The implications of the study findings for future research and clinical practice are also considered in this chapter.

Chapter 2: The illness experience

2.1 Introduction

This chapter sets the scene for this study and discusses different perspectives and approaches to the experience of illness. It starts by discussing the work of seminal authors, such as Kleinman (1988b) and Cassel (1982) who argue that disease and illness are two fundamentally different concepts. It then goes on to discuss how within current healthcare the concept of 'disease', with its close affinity to the biomedical model of care, continues to dominate, despite significant limitations being identified, particularly the passive role that it affords the patient and its oversimplification of the illness experience. This discussion then extends and encompasses alternative models which have been developed in direct response to the criticism of the biomedical model, where it is argued that these models offer a more humanistic perspective of the experience of illness, placing the patient at the fore and addressing the complexity and subjectivity of the illness experience.

2.2 Illness or disease?

The terms 'disease' and 'illness' have been discussed by medical anthropologists for decades to describe the different approaches to

health (Kleinman 1988a; Kleinman 1988b; Cassell 1982; Kleinman 1980). For example, Kleinman (1988a) argues that the two concepts (illness and disease) are fundamentally different from each other. He states that:

Disease is a problem from the practitioner's perspective. In the narrow biological terms of the biomedical model, this means that disease is reconfigured only as an alteration in biological structure functioning (Kleinman 1988a:5-6).

In contrast, he describes illness as being:

[T]he innately human experience of symptoms and suffering. Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability (Kleinman 1988a:3).

The disparities between the two phenomena are evident in Kleinman's (1988a) descriptions of the two states, with 'disease' using the 'lens' of the biomedical model to focus on the underlying pathology of the condition and appearing to neglect the perspective of the patient. 'Illness', in comparison, appears to be an inherently human experience that recognises the impact of a condition on the wider realms of a patient's life. This interpretation supports that of Cassel (1978) who states that 'illness' means what the patient feels

when he goes to the doctor and 'disease' to mean what he has on the way home from the doctor's office.

This humanistic perspective afforded by the model of illness is supported by Thorne who states:

...illness is experienced not as a factual clinical event, but rather as a lived, cognitive, emotive, social and even political event that is entered into by thinking, feeling and interpreting beings individually and collectively (Thorne 1999:398).

Furthermore, according to Robertson and Boyle, health and illness are as much social and cultural phenomena as they are biological (Robertson and Boyle 1984).

Whilst the works of the authors cited above (Kleinman 1988a; Kleinman 1988b; Cassell 1982; Kleinman 1980) portray illness and disease as two distinctly different concepts, there is debate within the literature regarding their conceptual boundaries. For example, it has been argued that the two concepts overlap, with the occurrence of disease often resulting in the experience of illness (Kleinman, 1980). However, in contrast, it has also been purported that the two states

can occur distinct from one another (Helman 1981). For example, Hypochondria has been used as an exemplar to demonstrate how illness can occur without the presence of disease (Cassell 1978). The same arguments have been made relative to the experience of disease, with conditions such as severe trauma and sepsis being used to describe the occurrence of disease that manifests itself so rapidly that illness does not have any time to follow.

The argument that disease and illness are distinct from one another is further supported by a recent study by Wikman, Marklund and Alexanderson (2005). Using cross-sectional data from comprehensive interview surveys with 3500 people on the concepts of illness, disease and sickness absence, they reported that there was little overlap between these different concepts of ill health and concluded that further research was required to explore why such disparities exist.

Such debate continues in current day literature, where it is contended that conditions such as Chronic Fatigue Syndrome do not 'fit' within the spectrum of disease, as they are poorly defined, have multiple potential aetiologies, and therefore do not confer within the discrete categories of the biomedical paradigm (Lloyd et al. 2000). However,

despite such debate being presented in the literature, the biomedical model of care, with its focus on disease, continues to dominate current health care today.

2.3 The biomedical model

The biomedical model, stemming from Virchow's conclusion that all disease results from cellular abnormalities (Porter 1997), has within it a number of key assumptions (Giddens 2009; Nettleton 2006; Wade and Halligan 2004) as detailed in table 2 below.

Table 2: Assumptions of the biomedical model
Disease is the deviation from normal biological functioning (Wade and Halligan 2004; Cassell 1982; Cassell 1978; Engel 1977).
Disease occurs naturally independent of social behaviour or influences (Nettleton 2006).
Health is the absence of disease and can only be restored using medical intervention. From this perspective, 'the human body is a machine and the doctor or surgeon is the mechanic who fixes it when something goes wrong' (Crossley 2000:2).
Each disease is caused by a specific, potentially identifiable source (Wade and Halligan 2004).
All diseases have distinguishable characteristics such as symptoms, and that these remain the same irrespective of the historical or cultural context in which they are situated (Giddens 2009).
Mind/body dualism: physical and mental health problems are separate entities (Wade and Halligan 2004).
Only medically trained health professionals have the expertise to diagnose health problems.
The patient is a passive recipient of health care (Bury 2001).
Ignores lay account of illness (Bury 2001).

2.3.1 Benefits of the biomedical model

The contributions of the biomedical model to healthcare cannot be ignored, with advances in the diagnosis and treatment of numerous conditions resulting in reduced rates of mortality and increased longevity in distinct patient populations worldwide (Gaede et al. 2008; Wade and Halligan 2004; Misselbrook 2001; Bunker 2001; Bunker 1995; Bunker et al. 1994). Examples of such improvements include advances in cardiac care where the use of thrombolysis, aspirin, angiotensin-converting enzyme inhibitors, statins and coronary artery bypass surgery have result in significant reductions in patient mortality compared to twenty years ago (Unal et al. 2005).

For other common conditions such as cancer, such improvements are also evident, with significant reductions in cancer incidence and mortality rates reported in the Western World (Jemal et al. 2011; Jemal et al. 2010; Ferlay et al. 2007a; Ferlay et al. 2007b). Such findings have been attributed to the advent of screening programmes (Sarkeala et al. 2008; Hakama et al. 2008), public health campaigns and advances in many treatment modalities such as chemotherapy and radiotherapy, which has resulted in people with cancer being diagnosed earlier and living with the disease for longer (McArdle et al. 2010; Westlake and Cooper 2008; Nilsson et al. 2004; Jonker et

al. 2000). Based on such developments, there is ongoing debate that cancer should be viewed as being a chronic illness (Cayless et al. 2010; Hubbard et al. 2010; McCann et al. 2010; Hubbard et al. 2006), as opposed to one which has historically been associated with significant suffering and poor survival rates.

However, in contrast, for developing countries, such improvements have not been observed, with cancer incidence and mortality rates reported to be rising (Jemal et al. 2011; Jemal et al. 2010) and this has been attributed to the combination of late stage diagnosis and poor access to timely and standard treatment. Based on the success of biomedical interventions in the Western World, such as programmes for tobacco control, vaccination, screening and public health campaigns, it has been advocated that such trends can be reversed in developing countries if similar interventions were to be delivered on a global basis (Jemal et al. 2011; Jemal et al. 2010). As such, there have been calls for health professionals, public health professionals and policy-makers to play an active role in accelerating the application of such interventions worldwide.

The significant benefits of the biomedical model on the health of the Western world have been demonstrated not only on a disease-

specific basis, but also generally. The seminal work of Bunker (2001; 1995; 1994) is one example, whereby via a meta-analysis of the literature, he attempted to quantify the benefits in morbidity and mortality from current Western medical practice and claimed from his findings that three of the seven years of increase in life expectancy since the 1950s could be attributed to medical intervention. Furthermore, he also estimated that medical intervention provided on average 5 years' partial relief from the deterioration in quality of life associated with chronic disease. Whilst Bunker's (2001; 1995; 1994) work can be critiqued on the grounds that it did not provide information on the criteria used for the selection of studies and that it focused on the results of only RCTs, the findings of his study do provide a crude measure of the benefits of the medical model in the Western world, and may therefore provide evidence to substantiate why this model of care remains prevalent in contemporary healthcare.

The above findings purporting the benefits of the biomedical model are further supported by studies which have demonstrated that reductions in mortality are greater for those conditions that are amenable to medical intervention compared to those that are not (Charlton and Velez 1986). Furthermore, it has been claimed that patients who have conditions that are 'receptive' to treatment have

on average an increased life expectancy of between 5-18 years compared to conditions where treatment regimes are not as responsive (Mackenbach 1996).

However, despite the evident success of the biomedical model in the field of medical science and its dominance within current healthcare systems, many of its assumptions and its utility and effectiveness within healthcare are being increasingly questioned (Giddens 2009; Nettleton 2006; Wade and Halligan 2004). Such challenges to the biomedical model have occurred over the past four decades and continue to attract much debate within the literature today. These challenges are discussed in the following sections.

2.3.2 Critique of the biomedical model

As previously stated, the critique of the biomedical model extends over a significant period of time. Most of this critique focuses on three main areas: refuting the anticipated benefits, the passive role of the patient, and the affinity of the model with reductionist methods of measurement. Each will be discussed in turn below.

2.3.2.1 Refute of the anticipated benefits of the biomedical model

Historically, challenges made towards the biomedical model of care were made by refuting some of its anticipated benefits. An example of this is the seminal work of McKeown (1976) who, by using historical analysis, claimed that improvements in health and decreases in mortality in the 1970s were not due to advances in science as assumed by many, but were due to the implementation of broad scale economic and social interventions that had taken place. His results therefore indicated that social conditions were a fundamental cause of human disease which was contradictory to the scientific assumptions of the biomedical model, that is, that disease occurs independently of social behaviour or social influence (Giddens 2009; Bynum 2008; Szreter 2002). The findings of McKeown (1976), whilst radical at that time and contested by others on the grounds of their lack of recognition of the significant contributions that medicine had made to the health and reductions in mortality of the population at that time (Bynum 2008), have nevertheless been highly influential in the recognition of the sociological perspective of disease and the acceptance of the role that culture and context play in the causation and experience of illness (World Health Organisation 2008; Bynum 2008; Szreter 2002).

This notion of the offered benefits of the biomedical model and the sociological perspective of disease was also the focus of Illich's (1975) seminal work on the iatrogenic consequences of medicine. He contends that biomedicine did more harm than good. As opposed to curing and healing, Illich (1975) argued that modern medicine did the opposite and contributes to illness through its iatrogenic effects (clinical iatrogenesis). He also argued that the increase in use of medical interventions created a 'morbid' society, as people focused on the domains of health and disease, which, in turn, created an artificial demand for medicine (social iatrogenesis). Furthermore, Illich (1975) claimed that this increase in demand for medical expertise resulted in a de-skilling of the patient, as people became more dependent on the medical system and unable to deal with their conditions themselves (cultural iatrogenesis).

Whilst Illich's (1975) critique of the biomedical model was made over three decades ago, many of the points he raised are however supported in modern-day literature where the iatrogenic consequences of medicines are increasingly being reported (Glover-Thomas and Fanning 2010; Dunne and Quayle 2001). Moreover, Illich's (1975) statements pertaining to the social and cultural iatrogenic consequences of the biomedical model appear to be warranted, with growing recognition by politicians and clinicians alike,

as healthcare systems cannot meet the current and future demands of its consumers. In response, many directives have been launched at policy level to encourage patients to undertake their own self-care and take responsibility for the management of their own conditions (Scottish Government 2007; Department of Health 2007).

The above response has highlighted how the biomedical model has been challenged by a number of scholars contesting its anticipated benefits and its ignorance of the sociological perspectives of disease. Whilst many of the challenges to this model were made over 30 years ago, many of the arguments made remain relevant and valid today, such as McKeown's (1976) contention of the influence of social conditions on the occurrence and experience of disease and Illich's (1975) claims that the benefits of the biomedical are outweighed by the associated harm. Another main critique of the biomedical model within the literature is based on the limited role that it affords to the patient and limited acknowledgement of lay accounts of illness. This observation will be discussed in the following section.

2.3.2.2 *The biomedical model and the patient*

The critique of the biomedical model extends to the role that the model affords to the recipient of healthcare – the patient. It is

argued that the biomedical model confers a paternalistic model of care where the doctor commands the medical knowledge and the patient is in a position of dependence (Kaba and Sooriakumaran 2007; Lupton 1997; Foucault 1980). Such views purport that the medical professionals enhance their position of power by assuming that it is their privileged right to define and treat illness, thereby subordinating the opinions and knowledge of lay people. It has been argued that this power relationship is more apparent in socio-economically disadvantaged groups *'whose lack of power is further entrenched through their social interactions with powerful doctors who seek to maintain the social status quo'* (Lupton 1997:100). This type of clinician-patient relationship is therefore said to deny individuals the right of self-determination and autonomy (Ho and Byluna 2008). However, it has been argued that this perspective of the medical encounter offers an exaggerated example of the doctor-patient relationship and, as stated by Atkinson (1995:33) *'..is exaggerated to the point that the lay client becomes not the beneficiary but the victim of the consultation'*.

With relevance to current-day medicine, the advent of models of 'patient-centred care' (Mead and Bower 2000) appear to be rebuffing the portrayal of the physician-patient encounter depicted in the biomedical model (Kaba and Sooriakumaran 2007; Lupton 1997;

Foucault 1980). There is a growing body of evidence to suggest that this culture of care is starting to change and patients are now encouraged to take a more active and autonomous role in their care (Hack et al. 2005). The once one-sided doctor-dominated relationship is beginning to be replaced by a patient-centred model of care where mutual participation and shared decision-making are central processes (Donaldson 2008; Kaba and Sooriakumaran 2007). Nurses have also made significant contributions to the development and delivery of patient-centred care, where the advent of nurse-led interventions has been reported to result in improvements in patient satisfaction, quality of care and result in cost reductions (Olsson et al. 2009; Wolf et al. 2008).

However, the passive role the biomedical model affords to the patient has been challenged on the grounds that it ignores the validity of lay accounts of illness (Kleinman 1988b; Engel 1977). Such a stance stems from the positivistic paradigms which govern this model of care. The biomedical model assumes that the scientific method is the best approach by which to study the body, with its belief that the 'truth' of the knowledge produced can only be verified through measurement and observation. Its links to positivism take on the assumption that the human body can be analysed independently of the mind and that reality exists outside the realms of subjective

human perceptions (Lincoln and Guba 1985). However, according to Bury (2001), lay accounts of illness are being increasingly accepted as valid sources of information. He asserts that the rise of the patient narrative can be attributed to a number of related factors, for example, the decline in the importance of biologically-driven phenomena such as infections, with a growing awareness of the impact of degenerative and chronic conditions (Bury 1997; Charmaz 1991; Bury 1991; Charmaz 1983; Bury 1982). Such awareness, Bury (2001) argues, has resulted in healthcare focusing more on the management and care of conditions rather than on their treatment and cure. Furthermore, he states that the wide availability of information available to patients via mediums such as the internet and media has resulted in a reduction in medical authority, as patients now have the information to challenge healthcare professionals and make their views count (Bury 2001).

The above literature, whilst recognising the significant contributions that the biomedical model has made to healthcare worldwide, also discusses how this model has been challenged on the grounds of its assumed benefits and its neglect of the sociological perspective of illness. It has also discussed how the biomedical model has been criticised for the passive role that it affords to the patient and its lack of recognition of lay accounts of illness. The next section will discuss

the most widely critiqued attribute of the biomedical model: its affinity with reductionist methods of measurement

2.3.2.3 Reductionism

A widely accepted critique of the biomedical model is the seminal work of Engel (1977), who, in the 1970s, forewarned of a crisis in the biomedical model of care due to its sole focus on the biological manifestation of disease. He argues that this focus on the physical dimensions of illness excludes the patient narrative and the social, psychological and behavioural dimensions of illness. He contends that this stance results in an oversimplification of the illness experience which, in reality, is much more complex than the biomedical model leads us to believe. According to Engel (1977), this oversimplification is partly attributable to the 'embrace' of the biomedical model with reductionist models of measurement. As Engel states:

Thus the biomedical model embraces both reductionism, the philosophic view that complex phenomena are ultimately derived from a single primary principle, and mind-body dualism, the doctrine that separates the mental from the somatic. Here the reductionist primary principle is physicalistic; that is, it assumes that the language of chemistry and physics will ultimately suffice to explain biological phenomena (Engel 1977:130).

As with Engel (1977), many of the existing critiques of the biomedical model within the literature are based on its reliance on reductionist methods of measurement and the way that they aim to reduce complex phenomena to their core physical elements; into units that can be measured and quantified (Wade and Halligan 2004; Willig 2001; Thorne 1999; Cassell 1982; Mishler 1979). It is argued that this focus on the physical dimensions of illness results in the exclusion of the '*human aspects*' of illness (Thorne 1999; Cassell 1982; Engel 1977) which does not help us to '*comprehend the whole person*' (Cassell 1982:643). Furthermore, according to Willig (2001), this exclusion of the human facets of the illness experience results in data being collected which have little resemblance to the actual experience in the context of a person's life and does not recognise the role of social, historical and cultural factors in the formation of knowledge.

This critique of the '*oversimplification*' of the biomedical model is strongly supported by the vast body of empirical evidence which highlights the complexity of the illness experience. The experience of chronic illness is one area where this critique is best exemplified, particularly in the works of scholars such as Bury (2001; 1997; 1982) and Charmaz (1991; 1983). Their research has highlighted the ways in which chronic illness impacts on daily living, social relationships

and people's sense of self and identity. Their research also focuses on the ways that individuals cope with the demands placed on them by their illness and its associated treatments and how they try to maintain a coherent valued sense of self throughout.

The focus of such studies has therefore been on the meaning of the experience of chronic illness and how people adapt and cope with their illness, highlighting the importance of understanding the contextual dimension of the experience of illness. Of particular relevance to this thesis is that it is argued that the experience of cancer has much in common with the experience of chronic illness, with many of the characteristics described above being exhibited by both of these patient populations (Cayless et al. 2010; Hubbard et al. 2010; McCann et al. 2010). This is of particular pertinence to the experience of lung cancer where many of the manifestations of the experience of chronic illness have been reported in this patient population. This includes a loss of personal and social identity (Chapple et al. 2004; Mathieson and Stam 1995), the inability to undertake previous activities of daily living (Quast and Williams 2009; Kiteley and Fitch 2006) and social isolation (Ekfors and Petersson 2004). It may be argued that such experiences are more profound in patients with lung cancer due to their poor survival rates,

and them having to deal with multiple distressing issues in a relatively short period of time.

Reductionist methods of measurement have also been criticised on the grounds that they aim to make generalisations about populations at the expense of an appreciation of the idiographic experience of illness. Furthermore, concern has been raised at the use of such generalisations in informing political and health reforms with the neglect of the perspectives of the individual (Thorne and Jillings 1996).

Carr and Higginson (2001) add to this critique of the use of reductionist methods and discuss how many of the quantitative measures used are derived from the perspective of '*experts*' (health professionals/academics) which have '*limited relevance*' to the world of the patient. This '*limited relevance*' is partly explained by health professionals' traditional focus on medical aspects of care which do not capture the '*far-reaching*' effects of illness on a person's life (Carter et al. 2004:612). This critique is also supported by published evidence which demonstrates the difference of patients, carers and health professionals' perceptions of illness; often what is deemed to

be important by the patient is not recognised by people caring for them (Kuther et al. 2006; Hill 2002; Nekolaichuk et al. 1999).

Related to the above critique and the argument that reductionist methods of measurement have 'limited relevance' to the individual, is a study conducted by Krishnasamy (2000) on the experience of fatigue in patients with advanced cancer. Using a case study methodology, she reported inconsistencies between quantitative fatigue measurements and the patients' narratives. She stated that quantitative measures oversimplified the experience of fatigue and did not capture the distress and meaning of the symptom in the individual's life and therefore conveyed '*little of the underlying reality*' (Krishnasamy 2000:412). She concluded that by continuing to measure complex phenomena using reductionist methods of measurement, '*many distressing facets of experience are likely to remain hidden from the clinical and research agenda*' (Krishnasamy 2000:411).

The above literature has provided a critique of the limitations of the biomedical model made over the past four decades and provides a current-day context to many of the challenges posed many years ago. Therefore, it is not surprising that, in light of such consistent

critique, a number of scholars have proposed alternatives to the biomedical model and these are discussed below.

2.3.2.4 *Alternatives to the biomedical model*

In light of the limitations of the biomedical model demonstrated above, a number of models have been developed which provide an alternative view of the domains of health and illness (Crossley 2000; Good and Good 1980; Engel 1977). Of note, is that the alternative models discussed below are those which have been identified in the literature as being developed in direct critique of the biomedical model.

One of the most influential of those models is Engel's biopsychosocial model of care (Engel 1977). This model of care hypothesises that biological, psychological and social factors all contribute in a combined manner to the experience of illness (Engel 1977). It has been described both as a 'philosophy of clinical care' and 'a practical clinical guide' (Alonso 2004; Suls and Rothman 2004; Borrell-Carrio et al. 2004; Engel 1977). On a philosophical level, it is a means of understanding how the experience of illness is affected by multiple factors from the molecular to societal influences (Borrell-Carrio et al. 2004). On a practical level, it has been described as an approach

which allows health professionals to recognise the importance of subjective experience in determining health (Borrell-Carrio et al. 2004).

Since its introduction, the biopsychosocial model of care has been widely adopted by a number of health-related disciplines such as medicine, nursing, and health psychology. However, despite its popularity and recognition, there is evidence within the literature to suggest that the biomedical model of care still dominates current healthcare today (Fava and Sonino 2008; Alonso 2004; Suls and Rothman 2004). Cited reasons for this continued dominance include the difficulty experienced by health professionals in competing with traditional biomedical models of care and that clinicians are still reluctant to integrate an alternative model into their treatment plans (Alonso 2004). Reasons for such reluctance include the increased demands that the delivery of the biopsychosocial model places on the health professional (Alonso 2004). It has been argued that the use of this model of care in practice brings to the fore a wider spectrum of patient need which requires a greater investment of time on behalf of the health professional, not only to deal with such needs but also to acquire knowledge to be able to address these needs (Alonso 2004). It has also been argued that the perpetual dominance of the

biomedical model is partly attributable to the way that health professionals, in their training and clinical practice, have been:

[E]ducated and socialized in a worldview that affords illness a concrete, objective meaning. This perspective privileges such factors as functional limitations, degree of pain, and certainty of prognosis , rendering them prominent and visible within health care discourse (Thorne 1999:398).

Since the introduction of Engel's biopsychosocial model (1977), a number of other models of health have been developed, which, like the biopsychosocial model, directly challenge the biomedical paradigm.

The work of Crossley (2000) in the area of health psychology is one example. She challenged traditional health psychology's attempt at delivering a biopsychosocial model of care on the grounds of its overuse of reductionist methods of measurement and analysis, which she claimed resulted in a failure to comprehend the crucial elements of human experience. As an alternative, she proposed a critical hermeneutic approach to health psychology, which she argued would facilitate *'a deeper understanding of both the psychological dimensions of human experience and also, relatedly, of the*

sociocultural dimensions of such experiences', appreciating the role of human agency and meaning in the illness experience (Crossley 2000:6). Within the hermeneutic approach, Crossley (2000) advocated the use of qualitative research methods which, as opposed to the reductionist methods employed in the mainstream branch, *'create a detailed and profound insight into a particular, perhaps unique, account or experience, rather than a set of broad generalisations about commonalities between different people'* (Crossley 2000:7-8).

Whilst the above challenges posed by Crossley (2000), with their particular relevance to the limitations of the use of reductionist methods in the measurement of subjective human experience, are supported widely in the literature, her work, nevertheless, was viewed as being radical by some of her contemporaries (Nicolson 2001; Owens 2001). Two direct critiques made in response to her paper have presented different viewpoints (Nicolson 2001; Owens 2001). For example, Nicolson (2001) agrees with much of Crossley's (2001; 2000) argument on the grounds of the limitations of the biomedical approach and adds to it by contending that health psychology's affinity with the biomedical model is preventing it from being recognised as a discipline in its own right. In comparison, Owens's (2001) response to the paper argues that the biomedical

model has not neglected the social and psychological factors of disease, and she states that she is not yet convinced '*that we should give up the undoubted power of scientific approaches in our pursuit of the understanding of how psychology relates to health*' (Owens 2001:263). However, irrespective of differing viewpoints, both scholars (Nicolson 2001; Owens 2001) agree that Crossley's (2001; 2000) vision for an alternative approach to health psychology did open up new avenues of exploration and contemplation of the future direction of the discipline as a whole.

As with Engel (1977) and Crossley (2000), Good and Good (1980) also proposed an alternative to the biomedical model of care: 'A Cultural Hermeneutic Model of Clinical Practice'. This model views the patient's illness as a '*syndrome of meaning*' (Good and Good 1980:180) with its purpose being to enable the clinician to understand the meaning of an illness in a person's life and to translate this information into clinical practice. Good and Good (1980) state that clinicians achieve this by decoding the patient's semantic network, which entails (as with classical hermeneutics) '*moving dialectically from the part (the "text", the symptom) to the whole (the "context", the illness network) and back again, to bring understanding of the illness from the sufferer's perspective*' (Good and Good 1980:180). As they state:

Symptoms do not reflect somatic abnormalities in any simple way, and the relationship among symptoms does not mirror a set of mechanistic or functional physiological relationships. Symptoms are irreducibly meaningful. Illness and symptoms are experienced as realities and thus are integrated logically and meaningfully (Good and Good 1980:191).

This focus on the semantics of the illness experience as afforded by Good and Good (1980), whilst in stark contrast to the biomedical model of care, does appear to be warranted based on the large body of evidence which demonstrates the central role that meaning plays in the experience of illness.

Seminal works from authors such as Frankl (1959), Cassel (1982) and Kleinman (1988b) argue that meaning is a fundamental dimension of being human and that illness and suffering cannot be comprehended without contemplating the concept of meaning (Cassell 1982; Frankl 1959). Such arguments are supported by a variety of other seminal authors on the role of meaning in the experience of illness, such as Sontag (1988; 1977), Frank (1991), and Zaner (2004). All have, in some way, described what the experience of illness is like for the ill, what it means to be ill and how individuals make sense of illness in their lives. For example, the work of Sontag (1988; 1977) has highlighted the negative cultural meanings that society appends to illnesses such as cancer and AIDS,

assuming that such diseases occur as the fault of *'someone who has indulged in unsafe behaviour'* (Sontag 1988:25). She describes how this assumption leads to a culture where the person is blamed rather than comforted about their disease, causing significant distress to the individual. Personal narratives such as those by Frank (1991) on the experience of serious illnesses such as cardiac disease and cancer, also highlight how *'illness leaves no aspect of life untouched'* (Frank 1991:6) and how *'when the body breaks down, so does life'* (Frank 1991:8).

This focus and importance on meaning also extends to the symptom experience. Using cancer as an exemplar, numerous studies have demonstrated how patients do not view symptoms through the narrow lens of the biomedical model, but view them as being meaningful experiences. For example, Ferrel and Dean's seminal paper on the meaning of pain (1995) reported how the participants in their study viewed pain as being a punishment, a sign of illness progression and of impending death, and such findings have been reported elsewhere in the literature (Lindqvist et al. 2006; Lindqvist et al. 2004). The symptoms of fatigue, breathlessness and weight loss have also been reported by patients with cancer to be symbolic of nearing death, feelings of being trapped inside a failing body and of being a burden to others (Wu and McSweeney 2007; Lindqvist et

al. 2006; Hopkinson et al. 2006; Gibson et al. 2005; O'Driscoll et al. 1999). The experience of the symptoms of weight loss and alopecia have been associated with feelings of stigma in patients with advanced cancer, often due to the overt visibility of these symptoms to others and their societal status as being 'cancer symbols' (Plough-Hansen 2007; Hopkinson et al. 2006; Wilson and Luker 2006; Chapple et al. 2004; Rosman 2004; Scambler 1988; Sontag 1988; Sontag 1977; Goffman 1963).

Therefore, as previously stated, the Cultural Hermeneutic Model of Clinical Practice advocated by Good and Good (1980) does appear to have a significant scientific basis to warrant its semantic approach. This model, as with the others described above, is in contrast to the biomedical model, and, to an extent, this is not surprising as they were all developed in direct response to the critique of the biomedical model and identified limitations of this model of care. Instead of focusing on the biological manifestation of disease, all of these alternative models advocate a wider appreciation of the context and impact of illness within a person's life. These models also highlight the importance of addressing the subjectivity of the illness experience, focusing on the idiographic and capturing experience in all its complexity, rather than trying to reduce and objectify it. These alternative approaches also pay homage to the patient narrative and

instead of excluding it, welcome its use in determining the meaning and the reality of the experience of the illness in a person's life.

It may, therefore, be argued that these alternative models afford a more humanistic approach to the experience of illness, which goes far beyond the confines of the biomedical model. It could be contended that such alternative models are more fitting to understand the complexities of the illness experience and in addressing the needs of patients. Having provided a critique of the biomedical model, and the alternative models of care offered in direct response to such challenges, the following chapter continues this discussion relative to the study of symptom clusters in patients with cancer.

Chapter 3: The study of symptom clusters in patients with cancer

3.1 Introduction

This chapter begins by defining what a symptom is, the different interpretations of the symptom experience, and the importance of symptoms in the experience of illness, particularly the experience of cancer. This discussion is then followed by an overview of research in the area of cancer symptom management, describing its journey from 2001, when the concept of symptom clusters was formally introduced within the cancer symptom management arena, to the present. Of note, is that since the formal introduction of symptom clusters into the cancer nursing literature, it has been described as a 'concept' (Barsevick 2007a; Barsevick 2007b; Dodd et al. 2001a; Dodd et al. 2001b), therefore, in order to maintain consistency, the term 'concept' is used throughout this thesis.

The sections that follow then focus the discussion on the concept of symptom clusters in patients with cancer, discussing the current scientific base which underpins the concept and the empirical evidence gleaned since the introduction of the concept almost 10 years ago. It concludes by highlighting the limitations of this body of

research, particularly its affinity to the biomedical model of care and its neglect of the perspective of the patient.

3.2 The definition of a symptom

A number of definitions of the term 'symptom' have been offered in the literature (Lenz and Pugh 2008; Armstrong 2003; Dodd et al. 2001a; Lenz et al. 1997; Teel et al. 1997; Lenz et al. 1995; McDaniel and Rhodes 1995; Rhodes and Watson 1987). For example, Lenz and Pugh (2008) define symptoms as being 'perceived indicators of change in normal functioning' and as '...red flags to the threat of health' (Lenz and Pugh 2008:164). Rhodes and Watson (1987), in their discussion of the concept of symptom distress, define symptoms as being subjective phenomena which symbolise to the individual a departure from normal function, sensation or appearance or as perceived indicators of change in normal functioning. Dodd et al (2001a) define a symptom as being 'a subjective experience reflecting changes in the biopsychosocial functioning, sensations, or cognition of an individual' (Dodd et al. 2001a:669). There are other definitions offered in the literature (Fu et al. 2004; Armstrong 2003; Teel et al. 1997; McDaniel and Rhodes 1995; Larson et al. 1994) however, common to all is the subjective nature of symptoms, that they denote a departure from normal functioning and that they are of particular relevance to the individual experiencing them.

As discussed in the previous chapter and highlighted by Tishelman (1991), the term 'symptom' can be construed in a number of ways, depending on the standpoint of the persons involved. Using the biomedical perspective, a symptom is viewed as being representative of a pathological pathway for diagnosis and cure. From a medical anthropological perspective, symptoms are viewed in a different way: not as being a 'reflection of the disease', but representing the meaning that the illness holds for the individual. Whilst this topic has attracted much debate in the literature (Krishnasamy et al. 2001; Corner and Bailey 2001; Tishelman et al. 1991), irrespective of the approach employed, all recognise the central role that symptoms play in the identification and management of disease and the negative impact that poorly controlled symptoms have on patient outcomes (Mansson et al. 2007; Trotti et al. 2007; Cleeland 2007; Lipscomb et al. 2007; Hegyvary 1993). Such findings are of particular pertinence to patients with cancer as they commonly experience multiple symptoms which are often severe, resulting in a high symptom burden (Breivik et al. 2009; Yamagishi et al. 2009; Cleeland 2007; Donovan et al. 2005; Miaskowski 2002; Vainio et al. 1996). Therefore, it is not surprising that a large body of evidence exists which has explored the experience of symptoms in patients with cancer. This is discussed below.

Historically, past research in the area of cancer symptom management has focused on the incidence and severity of individual symptoms such as pain, fatigue and depression (Richardson and Ream 1996; Ream and Richardson 1996; Sheehan et al. 1995; Ferrell and Dean 1995; Bendelow and Williams 1995; Winningham et al. 1994; Given et al. 1993; Blesch et al. 1991; Grossman et al. 1991; Padilla et al. 1990; Ferrell et al. 1989; Cleeland et al. 1986; Zigmond and Snaith 1983). However, this individual focus of study has been criticised on the grounds that it does not address the fact that people with cancer tend to experience multiple concurrent symptoms and that they rarely experience symptoms in isolation (Miaskowski et al. 2004b; Dodd et al. 2001a; Dodd et al. 2001b). Therefore, it has been argued that this approach does not reflect the 'real life' experiences of the patient (Barsevick et al. 2006b). Furthermore, the effectiveness of symptom management interventions developed in response to the findings of such studies have been questioned on the grounds of the high levels of morbidity which continue to be reported in patients with cancer (Breivik et al. 2009; van den Beuken-van Everdingen et al. 2007; Miaskowski et al. 2004b; National Institute of Health 2002). These findings may suggest that such interventions have not been as effective as previously assumed.

In response to some of the criticisms cited above relative to the study of individual symptoms in patients with cancer, Dodd and colleagues (Dodd et al. 2001a; 2001b) called for the consideration of the concept of 'symptom clusters' in oncology research (Barsevick 2007a). Such a concept, they argued, would address the fact that people with cancer rarely experience symptoms in isolation and would open up new avenues of exploration regarding ways in which the management of multiple symptoms in patients with cancer could be addressed.

However, it should be highlighted that symptom clustering is not unique to the area of oncology symptom management but has been used in other disciplines, such as psychiatry, psychology and general medicine, since the 20th century (Barsevick 2007a; Zimmerman et al. 2006; Shelby et al. 2005; Asmundson et al. 2000) where specific patterns of symptoms were thought to constitute a 'syndrome' or 'disease process' (Miaskowski et al. 2004a). Today, with advances in medicine and laboratory/radiological data assisting in the diagnosis of various conditions, the use of symptom clusters is less evident (Barsevick 2007a). However, within some disciplines, where the aetiology and underlying mechanism of certain conditions remains relatively unknown, symptom clusters are still used to assist in their diagnosis (Barsevick 2007a). Examples of conditions which still use

the concept of clustering to aid diagnosis include pre-menstrual conditions (Fugate Woods et al. 1999), chronic pain (Geisser et al. 1998), depression (Benazzi 2003) and gastrointestinal conditions (Vaira et al. 2001). However, as will be evident in the forthcoming sections, the concept of symptom clusters in patients with cancer has been applied in a different way from the disciplines described above. Instead of aiding in the classification of disease taxonomies, this concept has been used as a means of identifying relationships between symptoms with the aim of developing symptom management interventions targeted at treating clusters of symptoms.

As has been previously stated, the concept of symptom clusters in patients with cancer was first formally introduced into the area of cancer symptom management by Dodd et al (2001a) who highlighted the limitations of current symptom management approaches. They criticised past and current approaches on the grounds that they focused on the assessment and management of individual symptoms and questioned their effectiveness in dealing with the 'real life' symptom experiences of people with cancer who rarely experienced symptoms in isolation but who experience several symptoms at the same time (Dodd et al. 2001a). They introduced the concept of a symptom cluster as a potential solution to the management of symptoms in patients with cancer, claiming that it could lead to the

development of effective symptom management interventions which could target groups (clusters) of symptoms as opposed to individual symptoms and, thereby, offer a comprehensive approach to assessment and intervention. Since the formal introduction of the concept by Dodd and her team (2001a) there has been an upsurge of studies exploring the concept of symptom clusters in patients with cancer. However, on review of the literature it may be argued that this body of evidence has within it a number of significant limitations. These limitations will be discussed in the following sections relative to the scientific basis which informs the study of symptom clusters in patients with cancer and the empirical studies which have explored this concept to date.

3.3 Conceptual frameworks of symptom clusters

Whilst there are a number of theories, concepts and models which have been developed to conceptualise the symptom experience (Lenz and Pugh 2008; Humphreys et al. 2008; Kim et al. 2005; Goodell and Nail 2005; Parker et al. 2005; Armstrong 2003; Haworth and Dluhy 2001; Dodd et al. 2001a; Lenz et al. 1997; McClement et al. 1997; Teel et al. 1997; Lenz et al. 1995; McDaniel and Rhodes 1995; Larson et al. 1994; Rhodes and Watson 1987), none have been developed specifically to conceptualise the experience of symptom clusters in patients with cancer, but a few do claim to accommodate

the concept of symptom clustering within their conceptualisations. These include the Theory of Unpleasant Symptoms (Lenz and Pugh 2008), The Theory of Symptom Management (Humphreys et al. 2008) and the Symptoms Experience Model (Armstrong 2003). The core components of these theories and this model are detailed in table 3 below.

Table 3: Theories and model underpinning the study of symptom clusters in patients with cancer

Theory/Model	Domains	Components of domains
Theory of Unpleasant Symptoms (Lenz and Pugh 2008)	Influencing Factors	Physiologic Psychologic Situational
	Symptoms	Intensity Distress Timing Quality (cognitions – what it feels like to have the symptom)
	Performance Outcomes*	Functional Status Cognitive Functioning Physical Performance
Theory of Symptom Management (Humphreys et al. 2008)	Symptom Experience*	Perception of Symptoms Response to Symptoms Evaluation of Symptoms

	Components of Symptom Management Strategies*	Who (delivers?) What? When? Where? Why? How much? To whom? How?
	Outcomes*	Symptom Status Functional Status Emotional Status Mortality Morbidity and co-morbidity Self-care Quality of Life
	*All of the above influenced by person, environment, health/illness	Person (demographic, psychological, sociological, developmental) Environment (physical, social, cultural) Health/Illness (risk factors, health status, disease and injury)
Symptoms Experience Model (Armstrong 2003)	Antecedents	Demographic (age, gender, marital status, race, culture, role, education, socioeconomic status) Disease Characteristics (type and stage, type of treatment, co morbidities, and medical factors) Individual Characteristics (health knowledge, values, past experiences, sense of coherence)

	Symptom Experience	Frequency Intensity Distress Meaning
	Consequences	Adjustment to illness Quality of Life Mood Functional Status Disease Progression Survival

As can be seen in table 3, these theories and this model provide an abstract conceptualisation of the symptom experience. All focus in some way on factors that influence the symptom experience: the symptom experience itself and the outcome of symptoms. They all highlight the complexity of the symptom experience; how this experience manifests itself at many different levels from the cellular to the societal level but ultimately occurs at the level of the individual.

However, whilst these conceptualisations of the symptom experience informing the study of symptom clusters paint a very complex picture, we will see in section 3.4 (which discusses studies of symptom clusters in patients with cancer to date) that this complexity has not been addressed and how most researchers to date have adopted a biomedical approach, using reductionist methods of measurement which aim to reduce rather than embrace the complexity of this phenomenon. These studies therefore present the experience of symptom clusters in the form of statistical associations which, it may be argued, provides a narrow view of the experience of symptom clusters in patients with cancer and does not portray the full reality of the experience of this phenomenon in the person's life.

In addition to the theoretical and conceptual models above informing the study of symptom clusters in patients with cancer, definitions of symptom clusters available in the literature have also been used to guide research in this area. These are detailed in table 4 below.

Table 4: Definitions of symptom clusters in patients with cancer	
Authors	Definition
<p>Dodd et al (2001b)</p> <p>Dodd et al (2004)</p> <p>*Added to existing definition later in the literature</p>	<p>'when three or more concurrent symptoms are related to each other they are called a symptom cluster. The symptoms within a cluster are not required to share the same etiology'.</p> <p>*'Symptom clusters may have an adverse effect on patient outcomes and may have a synergistic effect as a predictor of patient morbidity'.</p>
<p>Kim et al (2005)</p>	<p>'when 2 or more symptoms that are related to each other and that occur together. Symptoms clusters as composed of stable groups of symptoms, are relatively independent of other clusters, and may reveal specific underlying dimensions of symptoms. Relationships among symptoms within a cluster should be stronger than the relationship among symptoms across different clusters. Symptoms in a cluster may or may not share the same etiology'.</p>

On observing the previous definitions of symptom clusters offered in the literature, it is evident that there are number of shared

characteristics, for example, the concurrence of symptoms, the requirement that symptoms within a cluster are related to each other and that they do not need to share the same aetiology. However, both definitions contrast with respect to the number of symptoms within a cluster and whether symptom clusters impact on patient outcomes.

Relative to the number of symptoms in a cluster, we can ask which definition is correct. Is it defined as two or more symptoms as advocated by Kim et al (2005) or three or more symptoms as advocated by Dodd et al (2001b)? Such differences in definitions of the same phenomenon leave researchers conducting research in this area being faced with the dilemma of which definition to use. As we can see in appendix 5, this contradiction has led to different research teams using different definitions (Glaus et al. 2006; Bender et al. 2005). There are also some examples of studies where clusters have been identified using the two-symptom criterion that would not have met cluster status if the three-symptom criterion had been applied (Maliski et al. 2008). Therefore, such lack of consensus in definitions undermines the findings of such studies and questions what findings are valid. To answer this question regarding the validity of the results gleaned from studies of symptom clusters in patients with cancer, some scholars may explore the scientific base informing such

definitions. However, it may be argued that the scientific base underpinning both definitions of symptom clusters in patients with cancer is weak. For example, Dodd and her team (Dodd et al. 2001b) have not offered any rationale in the literature for their definition of a symptom cluster. In comparison, whilst Kim and her team (2005) did derive their definition using concept analysis, they used literature predominantly from the disciplines of psychology, psychiatry and general medicine, which is not the context in which the intended definition was proposed to be used. This neglect of context in the process of concept development has been criticised by a number of scholars (Hupcey and Penrod 2005; Paley 1996) and has been argued to result in a concept being developed which has little relevance to the field in which it was originally intended to be used, being described by Paley (1996) as an 'arbitrary and vacuous exercise' (Paley 1996:578).

In addition to difference in characteristics of symptom clustering offered in the two definitions, they can also be critiqued on the grounds that they afford little detail on the attributes that they do define. Both definitions state that symptoms within a cluster should be related, however, they offer no detail on the nature or the magnitude of the relationship. Once again this leads to researchers having to make their own interpretation regarding the relationships

within a cluster. As we can see in appendix 5, this ambiguity results in a variety of different approaches being used to provide evidence to substantiate the formation of a cluster, with this eclectic mix of approaches preventing any meta-analysis of the data being conducted.

Current definitions of symptom clusters in patients with cancer can also be criticised on the grounds that they focus solely on the objective characteristic of clustering, paying no homage to the subjectivity of the symptom experience at the level of the individual. As discussed in the previous chapter, this focus on objectifying and defining has close affinity with the biomedical model which has received criticism for the narrow lens that it affords to the experience of illness. It may be argued that by framing current definitions of symptom clusters in this manner we are perpetuating this biomedical focus on the study of symptom clusters and forgetting the 'person' in symptom clusters research. Such observations call for the subjective exploration of this concept from the perspective of the patient in order to bring their perspective into this important and emerging area of cancer symptom research.

From the above literature, it is evident that the current scientific base underpinning the study of symptom clusters is weak. Such claims can be made when taking into consideration the lack of any dedicated theoretical framework developed intentionally to accommodate the concept of symptom clusters in patients with cancer, lack of evidence substantiating current definitions, lack of consensus between existing definitions, lack of detail regarding identified attributes of symptom clustering and their biomedical focus which ignores the perspective of the patient. However, despite such limitations in the definitions of symptom clusters available in the literature, they have been extensively used to guide research into this area of cancer symptom management. This observation will be discussed in the section that follows.

3.4 Empirical studies of symptom clusters in patients with cancer

Since the formal introduction of the concept of symptom clusters in patients with cancer in 2001, there has been a dramatic increase in the number of empirical studies conducted in patients with cancer exploring this concept and these are detailed in appendix 5.

On review of these studies of symptom clusters in patients with cancer since the formal introduction of the concept in 2001 to the present, it is apparent that there are a number of limitations, with the most significant limitation being that, as a body of research, it has neglected the perspective of the patient. This major limitation is discussed in the following literature relative to the samples of patients recruited to studies, the methods of data collection employed in studies, and the methods of analysis used.

Relative to the samples of patients recruited to studies of symptom clusters in patients with cancer, a significant criticism of the sampling approaches adopted to date is the way that most studies have employed heterogeneous patient samples (Molassiotis et al. 2010; Cheung et al. 2009; Yamagishi et al. 2009; Yeh et al. 2008; Olson et al. 2008) consisting of patients with various cancers, at various stages of disease and receiving an array of different treatments. It may be argued that this eclectic mix of patients neglects the needs of patients both at a group level and also at the level of the individual.

At a group level, there are numerous studies which detail how people with different cancer types experience a different profile of symptoms and have different needs (Sanders et al. 2009; Gwede et al. 2008;

Jiong and Girgis 2006; Glaus et al. 2006; Cooley 2000; Arbuckle et al. 2000). At an individual level, the theories of the symptom experience already mentioned in chapter 3 (Lenz and Pugh 2008; Humphreys et al. 2008; Armstrong 2003; Larson et al. 1994) and also empirical studies exploring the experience of symptoms in patients with cancer (Miaskowski et al. 2006; Kiteley and Fitch 2006; Knobf 2001; O'Driscoll et al. 1999; Wells 1998; Richardson and Ream 1996), all agree on the importance of understanding the experience of symptoms at the level of the individual within the context of his or her life.

This lack of focus on the experience of symptom clusters within specific cancer types, and at the level of the individual is of particular concern to the study of symptom clusters in patients with cancer where repeated calls for the clarification of the concept have been made in order to determine the critical elements that need to be met to constitute a symptom cluster (Hadi et al. 2008b; Miaskowski and Aouizerat 2007; Barsevick 2007b; Kim et al. 2005; Dodd et al. 2004). According to Dodd (2004) the study of symptom clusters in patients with cancer is in the phases of concept exploration and clarification, where the concept has been introduced in the literature but *'it is too early to articulate its definite properties and potential explanatory power'* and where refining of the concept is required to

'resolve the conflicts about meaning and definitions' (Dodd et al. 2004: 77). It may be argued that clarification and identification of the core characteristics of symptom clusters can only occur if we move away from this heterogeneous approach and pay closer attention to the experience of these symptom clusters within defined patient groups and at the level of the person. If we do not do this, then we run the risk of the concept remaining poorly defined and its critical elements remaining unrecognised.

This critique of lack of patient focus in the study of symptom clusters in patients with cancer continues into the methods of data collection employed and the analysis strategies adopted. From appendix 5, it is evident that all of the studies listed (apart from three) have used quantitative methods of data collection. The limitations of the use of reductionist methods of measurement have been discussed in greater depth in the previous chapter, however, overall it has been argued that such approaches oversimplify and decontextualise the illness experience, bypassing the patient's verbal account and conveying little of the underlying reality or meaning of the experience to the patient. As highlighted on a number of occasions throughout this thesis, such neglect of the perspectives of the patient are of great concern, and may be viewed as a considerable limitation in the evidence underpinning the study of this phenomenon to date.

Linked to this critique of the use of quantitative methodology is the large variety of data collection tools used, some of which were not developed specifically to assess symptoms in patients with cancer (Yeh et al. 2008; Maliski et al. 2008; Bender et al. 2008a; Fox and Lyon 2006). Such observations have a number of implications. Firstly, it has been recognised that the types of questionnaires used in a study will, in part, determine the cluster of symptoms identified (Lopez et al. 2011; Molassiotis et al. 2010), and this is evidenced in appendix 5, where there is an extensive list of different symptom clusters being identified in different patient populations. However, on a practical level, how can researchers and clinicians deal with such variety, and how do they decide which findings are the most relevant to practice? It may be argued that the only way that such decisions can be made is to complement such findings with patient-centred inductive approaches which can offer clarification from the perspective of the patient as to which clusters appear to be most meaningful and relevant in the context of their lives. Secondly, for the studies that used tools which were not designed purposively to measure symptom in patients with cancer (Yeh et al. 2008; Maliski et al. 2008; Bender et al. 2008a; Fox and Lyon 2006), at the most fundamental level, how can we be sure that their measurements are valid and are therefore meaningful?

Linked to the predominant use of quantitative methods of data collection is the use of statistical analyses to provide evidence of symptom clusters in patients with cancer. A wide array of statistical approaches have been employed in studies to date, including simple correlations (Maliski et al. 2008), factor analysis (Bender et al. 2008a; Chen and Lin 2007), cluster analysis (Yeh et al. 2008; Glaus et al. 2006; Miaskowski et al. 2006), principal component analysis (Chow et al. 2007), hierarchical multiple regression analysis (Barsevick et al. 2006a), and mixed effect growth curve models (Wang et al. 2006). Linked to each statistical approach is a different set of assumptions regarding the nature and magnitude of relationships between symptoms in a cluster. Therefore, this leads to different clusters of symptoms being identified based on sets of different criteria and statistical assumptions. Once again (as with the variety of data collection tools used), this variability in approaches used poses problems for the interpretation of findings of such studies and their practical application in clinical practice.

Another significant limitation relative to the methods of data collection used in the study of symptom clusters in patients with cancer is the significant use of secondary data analysis in the current body of evidence. The results of such studies can be questioned on a number of grounds, for example, the samples and methods of data

collection used were not selected purposively to explore symptom clusters in patients with cancer. It has also been argued that the use of such approaches results in the formulation of research questions that are data driven rather than driven by the need for new or further knowledge about a phenomenon (Hofferton 2005). Therefore, both of these points raised pose a significant concern and questions the validity of the results of such studies, and their appropriateness in determining symptom clusters in patients with cancer.

As intimated on a number of occasions in this thesis, this inconsistency in approaches to the study of symptom clusters in patients with cancer may, in part, stem from the lack of conceptual clarity and the abstractness of current definitions, which leaves researchers having to decide for themselves characteristics which constitute evidence of symptom clustering. It may be argued that the only way that such limitations can be overcome is to explore the concept of symptom clusters from the perspective of the person experiencing it; only then will the 'essences' of the phenomenon come to light, providing a framework to direct further research in this area.

Supporting this patient-centred approach are the findings of the only three studies published in the literature to date which have utilised a qualitative approach relative to the study of symptom clusters in patients with cancer (Lopez et al. 2011; Molassiotis et al. 2010; Molassiotis et al. 2008). However, it should be noted that two of the studies cited above (Molassiotis et al. 2010; Molassiotis et al. 2008) were not intended primarily to explore the concept of symptom clusters in patients with cancer, but engaged in the concept in the presentation and discussion of their findings.

One of the studies (Molassiotis et al. 2008) explored the experience of chemotherapy related nausea in patients with cancer and, using content analysis, reported that participants' narratives of the symptom often concurred with other symptoms, suggesting that such findings provide preliminary evidence to support a cluster of symptoms consisting of nausea, loss of appetite, taste disturbance, vomiting and 'possibly' intolerance of smells.

The second study by the same authors (Molassiotis et al. 2010) reported respiratory clusters of symptoms (cough, breathlessness, and fatigue) which played a central role in the participants' symptom experiences a year after diagnosis and that these symptoms were

often the ones that patients felt were of greatest prominence in their lives. Of note is that this study was a secondary analysis of an existing data set and therefore had inherent limitations, as discussed previously. Furthermore, whilst the authors claimed to use IPA as a method of data analysis, the descriptive level of the findings presented in this paper suggests otherwise, as they do not confer with the deep level of analysis associated with this methodology and, therefore, the depth of findings expected in such studies.

The most recent study published (Lopez et al. 2011), unlike the two previous studies (Molassiotis et al. 2010; Molassiotis et al. 2008), did aim to explore patient narratives regarding the development and coexistence of symptoms in patients with gynaecological cancer, using data from qualitative longitudinal interviews over a 12-month period. Using content analysis, four symptom clusters were identified from the participants' narratives (Lopez et al. 2011), which included:

- Tiredness, sleeplessness, pain, depression
- Hair loss, ocular changes, body image, identity experience and anxiety
- Nausea, loss of appetite, taste changes, bowel function, weight changes, distress

- Numbness and tingling sensations in the hands and feet, restlessness, sleeplessness, and depression

Whilst the findings of the study do contribute to the body of research pertaining to the study of symptom clusters in patients with cancer on the grounds of its qualitative approach, it may also be argued that that the use of content analysis provides only a descriptive account of the experience of symptom clusters in patients with cancer. Furthermore, it has been contended that this approach has an affinity with reductionist methods of measurement, and often results in the oversimplification of phenomenon which are by their very nature complex (Weber 1990).

Outcomes of the studies by Lopez et al (2011), Molassiotis et al (2010) and Molassiotis et al (2008), highlight that the patient narrative is one way to elicit the occurrence of symptom clusters, suggesting that the statistical analysis approaches more widely utilised in the past, may not be the only way to identify and comprehend the existence and experience of symptom clusters in patients with cancer. Such an assertion has been previously posed by Kim et al (2005) who ask 'Are symptom clusters that are identified by statistical methods theoretically or clinically useful? Or are there better methods to identify symptom clusters and what are they?'.

Unless we explore symptom clusters from a patient perspective, this question will never be answered.

Therefore, in conclusion, whilst the study of symptom clusters in patients with cancer has opened up new avenues for research into cancer symptom management identifying symptom clusters in various patient populations, it can be argued that the theoretical basis underpinning this body of research is weak and that this lack of conceptual clarity has resulted in the production of a disparate body of research which is limiting the transference of this knowledge into clinical practice.

It may be postulated that in order to address such limitations, the core 'essences' of the phenomenon need to be identified (Krishnasamy et al, 2001), to provide researchers conducting studies in this area, clarification of the defining attributes of the phenomenon in which to guide future research. It may argued that in order to identify the core 'essences' of this phenomenon, then we need to explore the phenomenon from the perspective of the patient (Krishnasamy 2000) as they are the experiential expert.

Of relevance to the study of symptom clusters is that to date, no study has explored the lived experience of symptom clusters in patients with cancer and this itself may be viewed as being a significant limitation in this body of research. It may therefore be argued that in order to strengthen the scientific base and advance the concept of symptom clusters in patients with cancer, we need to explore the experience of symptom clusters from the perspective of the patient; we need to bring the 'person' in.

Chapter 4 Methodology

This chapter of my thesis discusses my methodological approach and describes the methods that I selected to explore the lived experience of symptom clusters in patients with advanced lung cancer. Firstly, I discuss the limitations of the predominantly quantitative approach to the study of symptom clusters and why a qualitative approach was selected. I then discuss epistemologies which underpin qualitative research methods and set out my philosophical position. This is then followed by a discussion of qualitative research methodologies providing a rationale for why Interpretative Phenomenological Analysis (IPA) was selected to explore the experience of symptom clusters in people with advanced lung cancer.

Chapter 3 of this thesis discussed the concept of symptom clusters in patients with cancer and highlighted a number of theoretical and methodological limitations in symptom clusters research to date (Kim et al. 2005). One area which was highlighted was the predominantly quantitative approach which has been used by researchers to identify and measure symptom clusters and the utility of such an approach has been questioned on the grounds that they reflect little of the

underlying reality of the experience of symptom clusters within a person's life (Willig 2001).

However, whilst recognising the contributions that such approaches have made to the study of symptom clusters in patients with cancer to date (see chapter 3), for subjective '*lived*' manifestations, such as symptoms, which '*represent expressions of the reality of the patient's world*' and are '*linked to the stresses and experiences of that person, composed of both cultural and personal meaning*' (Tishelman et al. 1991:1230), it may be argued that they neglect the context and meaning associated with the symptom experience and convey little of the underlying reality (Krishnasamy, 2000: 41). Furthermore, it has been advocated that before measurement can take place, we need to explore the meanings those particular phenomena have to the person experiencing them. As Krishnasamy (2000) states:

Without securing meaning before measurement, it is unlikely that an instrument will provide data which can contribute to an understanding of how the phenomena under investigation impact on the lives of the participants and what factors exacerbate or relieve it (Krishnasamy 2000:411).

To date, no studies of symptom clusters in patients with cancer have explored the lived experience, meanings and context which shape this phenomenon from the patient's perspective. Therefore, the current evidence base, which has predominantly used quantitative approaches, may be said to be fundamentally lacking. Furthermore, it could be argued that without the exploration of the experiences, context and meaning of poorly understood phenomena, such as symptom clusters, '*future research of poorly understood phenomena cannot be generated with any degree of certainty*' (Krishnasamy et al. 2001:412). Therefore, it appears that in order to develop and build upon the current evidence and theoretical basis of the concept of symptom clusters in patients with cancer, it is imperative that we explore and understand the experiences, context and meanings which surround this phenomenon.

4.1 More than a method

In contrast to quantitative methodologies which have predominantly been used in the study of symptom clusters to date (which, in turn, focus on causal relationships explicated in terms of observational statements, verifications and predictions), qualitative methodologies offer alternate ways of exploring human behaviour. They express a preference for contextual understanding and are interested in the meanings that an individual attributes to events (Willig 2001;

Barbour 2000). Qualitative approaches aim to understand experience from the perspective of those who live with it (Schwandt 1994) and all have a concern with the richness of the human experience (Ashworth 2003).

Such an approach appears to be a suitable approach to explore the experiences, context and meanings of symptoms clusters in patients with cancer. However, there is not one but many qualitative research methodologies which have a shared concern with context and meaning; many of them are deeply rooted in various theories of knowledge (epistemology) which make assumptions about 'how, what and can we know about the world' (Willig 2001:2) and the claims that such knowledge can make on the subject being studied (Green and Thorgood 2005).

Therefore, it is important that when selecting a qualitative methodology, the researcher adopts an epistemological position in order to be clear about the objectives of their research and to know what kinds of things it is possible for them to find out about the phenomenon under investigation (Reicher 2000). As stated by Reicher (2000), qualitative research methodologies '*have different*

philosophical roots, different theoretical assumptions and they ask different types of questions' (Reicher 2000:4).

Qualitative researchers can adopt a variety of epistemological positions and there are different ways of conceptualising these epistemological positions assumed by the different approaches to qualitative research (Reicher, 2000; Madill, 2000). However, at the most fundamental level, most methods share an assumption that there is no objective reality and that knowledge and its production are context-specific (Lyons and Coyle 2007). Madill (2000) conceptualised the differences in epistemological positions of qualitative research in terms of a continuum where on one end stands realist epistemologies (naïve, scientific, critical) and at the other end, constructionist (contextual and radical).

Realist epistemologies include naïve, scientific and critical approaches. Naïve realism is linked to the correspondence of the theory of truth which assumes reality can be discovered with the appropriate methods and that it exists independent to our perceptions of it, that is, that there are phenomena out there waiting to be discovered (Madill et al. 2000). Scientific realism views the scientific method as being the best mode of inquiry and that the

world described by science is the real world. In comparison to naïve and scientific realism, critical realism demonstrates a subtler form of epistemological realism in that it recognises that knowledge is not objective and therefore assumes that all knowledge is context-specific and influenced by the perspective of the perceiver and therefore admits a degree of subjectivity (Madill, 2000).

A constructionist epistemology advocates that 'human experience including perception is mediated historically, culturally and linguistically' (Willig, 2001:7). Therefore, a constructionist approach, in contrast to a naïve or scientific realist approach, believes that there is not an objective reality or truth waiting to be discovered. Rather, the constructionist believes that we construct reality in our given situations and therefore it follows that knowledge and understanding are highly contextual and situation-dependent; therefore, there is not one but many insights into the same phenomenon (Willig, 2001; Madill, 2000). Constructionism is therefore relative in that it does not privilege any picture of reality but views all to be equally acceptable and valid. In the research process, it emphasises the constructive nature of the participant-researcher interaction and their co-construction of meaning and therefore views researchers not as observers (as in many quantitative approaches) but as being an integral part of the research

process (Pidgeon and Henwood 1997). Constructionism emphasises the role of language and sees it much more than a medium to transport an accurate and straightforward description of a given reality. With this approach, language is seen as a set of social practices that perform part of the process of constructing reality (Willig 2001).

There are many constructionist epistemologies and how far along the continuum the researcher stands is a matter of their epistemological position. For example, the contextual constructionist expands one of the main tenets of constructionism in relation to the belief that all knowledge is context-sensitive and that it is integral to human experience (Jaeger and Rosnow 1988). According to Jaeger and Rosnow (1988), *'contextualism highlights that human activity does not develop in a social vacuum but is vigorously situated within a socio-historical and cultural milieu of meanings and relationships'* (1988:65). At the end of the constructionist continuum is the radical constructionist, who challenges the *'notion that there can be any absolute foundations for knowledge'*, and who *'is characterised by a profound distrust of the idea that language can represent reality'* (Madill et al. 2000:12)

4.2 My epistemological position

As has been previously stated, it is important that when selecting a qualitative methodology the researcher adopts an epistemological position in order to be clear about the objectives of their research and to know what kinds of things it is possible for them to find out about the phenomenon under investigation (Reicher 2000).

As a researcher, I reject the notions of naïve and scientific realist stance in that I do not believe that there is one single objective reality, independent of our perceptions of it, or that the scientific method is the only true way to access the real world. I do have an affinity to the critical realist approach in that I do believe that there is a real world, but that knowledge of it is influenced by the perceptions of the person in the context of their lives. I identify with many of the assumptions made by constructionist theories in recognising the centrality of historical, social and cultural processes on how we experience and understand our lives, resulting in not one but many knowledges about a phenomenon. I have a particular affinity to the focus of the contextual constructionist and the importance of context in knowledge production. However, I do challenge radical constructionist approaches and how they contest the notion of there being any foundation for knowledge. I am also critical of constructionist approaches and how they do not take into account the

extra discursive dimensions such as the body which 'obscures and downplays the significance of its functional, physiological, hormonal, anatomical and phenomenological aspects' (Cromby and Nightingale 1999:11). This point is supported by Broom and Willis (2007) in their critique of constructionist approaches, who ask: '*What can be more real than cancer, pain or diabetes?*' (Broom and Willis 2007:27). For the study of 'lived' phenomena such as symptoms, which have physical dimensions, it is imperative that the body is not '*treated as a mere metaphor*' (Cromby and Nightingale 1999:11).

Therefore, in conclusion, I am advocating a qualitative approach to the study of symptom clusters in patients with cancer which is informed by a contextual constructionist approach but which criticises such approaches for their ignorance of extra-discursive dimensions such as the body. As has been previously stated, there are many qualitative research methodologies however it is beyond the scope of this thesis to discuss them all. In light of the researcher's epistemological position, this thesis will discuss qualitative research methodologies which are informed by constructionist epistemologies, such as social constructionist versions of Grounded Theory, Discourse Analysis and Interpretative Phenomenological Analysis (Willig, 2001), and, in doing so, will provide the justification of why the

Interpretative Phenomenological Analysis (IPA) method was selected for this study.

4.3 Qualitative research methodologies

As has been previously stated, this section of the thesis will discuss qualitative research methodologies which have been linked to constructionist theories and will provide a rationale for the selected method of IPA to explore the lived experience of symptom clusters in patients with advanced lung cancer.

Social constructionist versions of Grounded Theory have been linked to a contextual constructionist epistemology. This methodology was originally developed by Glaser and Strauss (1967) in response to their disdain at the way existing theories dominated research. Their aim was to develop new 'contextualised' theories which were grounded in the data from which they emerged.

Since its introduction, a number of versions of Grounded Theory have evolved from the literature including the contextual constructionist versions (Mills et al. 2006) which have been developed in response to criticism of the ontological and epistemological origins of the earlier

versions. Much of this debate has stemmed from the inductive nature of Grounded Theory and the terms such as 'emergence' and 'discovery' of categories from the data, suggesting that the researcher uncovered something that was already there and therefore had no constructive role in this process. Such assumptions were therefore thought to ascribe to positivistic positions which hold that there is a direct correspondence of things in the world and our perception of them; thus, it is possible to obtain accurate knowledge of things in the world, provided we can adopt (Charmaz 2000) an impartial, unbiased and objective viewpoint. The social constructionist versions, such as the ones developed by Strauss and Corbin (1994) and Charmaz (2000), contested this viewpoint and argue that categories and theories do not simply emerge from the data but are constructed by the researcher through their interaction with the data. With this constructionist version of Grounded Theory, the role of the researcher is acknowledged as is what he or she brings to the research process (Charmaz 2000; Strauss and Corbin 1994). Therefore, in this instance, the theory reflects only one version of the data and subscribes to relativist positions on the nature of knowledge.

Whilst social constructionist versions of Grounded Theory have an affinity with the epistemological stance of the researcher and

therefore appeared to be an 'attractive' methodology for researchers wanting to explore the experience, meaning and context of symptom clusters in patients with cancer, such an approach was not thought to be suitable for the following reasons outlined below. Grounded theory was originally developed to theorize social processes and aimed to answer sociologically derived questions (Charmaz 2000). Its suitability to answer research questions regarding the meaning and nature of experience have been questioned (Willig, 2001) with some advocating the use of phenomenological types of inquiry for this. Therefore, as the research questions asked in this study are exploring the experience of people with advanced lung cancer who are experiencing symptom clusters, Grounded Theory was felt to be an unsuitable research methodology to answer such questions. Furthermore, one of the main tenets of Grounded Theory is theory generation and this is not one of the aims of this study.

Another qualitative research methodology which has been linked to constructionist theories is Discourse Analysis. This term is used to describe a number of qualitative approaches which focus on how people construct meaning through the use of language (Lyons and Coyle 2007). Therefore, such approaches are critical of cognitivism (Willig, 2001) and do not view the role of language as reflecting reality by describing experiences or revealing underlying

psychological process. Rather, they view language as a tool which constructs reality; *'it examines how people use language to construct versions of their worlds and what is gained from these constructions'* and therefore adopts a social constructionist position (Lyons and Coyle, 2007; 100).

There are two main approaches used in the study of discourse; Discursive Psychology and Foucauldian Discourse Analysis (Willig, 2001). Whilst both approaches agree on the discursive construction of reality and are therefore critical of cognitivism (that is to say that language provides a way for individuals to express what is in their minds), they, however, differ by the types of questions that they aim to answer and in the intellectual traditions which inform these questions.

Discursive Psychology stems from ethnomethodology and conversational analysis and is concerned with discourse in relation to how participants use language to negotiate and manage social interactions, and how they use language to achieve objectives (Potter and Wetherell 1987). Issues such as 'stake' and 'interest' are therefore interesting concepts to the Discursive Psychologist. Foucauldian Discourse Analysis, in contrast to viewing how people

use language to achieve objectives, is interested in how people use the discursive resources available to them ('discursive economy') within a context and how this constructs power relations and a sense of self (Willig, 2001). In this sense, discourse is viewed as having the ability to facilitate and control what can be said by an individual and the setting it is said in. Whilst both approaches agree on the linguistic construction of social reality, they diverge on the existence of reality, independent of language. Discursive psychology focuses exclusively on language and therefore ascribes to the radical constructionist position that there can never be any truth about a phenomenon as this is socially constructed. Foucauldian Discourse Analysis, however, holds on to the tenet that there is some reality which is independent of language (Willig 2001).

Whilst these approaches offer a sophisticated understanding of the use of language which is an attractive feature to some, their dismissal of the role of cognitions and their sole focus on language mean that they are not interested in mental processes and how they influence an individual's behaviour. Therefore, as this study is aiming to explore the experience, context and meanings of symptom clusters in patients with advanced lung cancer, it is important not only to focus on how people talk about a phenomenon but also to understand what they think about it. Therefore, it is important that that these

cognitions are addressed in order to answer the research questions posed. Therefore, on these grounds, Discourse Analysis was not selected for this study.

Having presented and discussed qualitative methodologies linked to the epistemological stance of the researcher and providing justification for their rejection in the current study, the methodology employed in this current study (Interpretative Phenomenological Analysis) will be discussed and contrasted to the previous approaches in order to provide justification for its selection.

Interpretative Phenomenological Analysis (IPA), as with the previous methodologies discussed, is linked to a contextual constructionist stance (Willig, 2001). It is ontologically rooted in critical realism believing that there are stable and enduring features of reality that exist outwith human conceptualisation and that different accounts of phenomena are possible because people experience different components of reality (Smith et al. 2009a).

IPA has been linked to the social cognition paradigm in that it assumes a connection between what people say and what they think

about phenomena. However, it does not believe this link to be direct in that it recognises the various linguistic abilities that people have in expressing themselves and also that they may not wish to disclose certain information (Smith and Eatough 2006). IPA also recognises the role that language plays in how individuals make sense of their lived experience and, in turn, how researchers make sense of the way individuals related these experiences. Therefore, IPA is said to have some similarities with discursive approaches in their focus on the use of language. However, IPA differs from discursive psychology (which is radically critical of cognition) on the view that reality is only constructed through language and that we can only refer to the world that we construct in this way (Smith, 2007). As stated by Smith and Eatough, *'IPA would disagree with a claim that language is the sole or primary constructor of reality'* (Smith and Eatough 2006:326).

One of the main theoretical touchstones of IPA is phenomenology, which is concerned with human understanding. It originated from the works of Edmund Husserl (1962) who has commonly been deemed to be the 'father of phenomenology'. His philosophical ideologies gave rise to the descriptive phenomenological approach (Cohen 1987; Husserl 1962). He argued that consciousness is the medium with which all human phenomena are experienced (Giorgi 2005) and believed that it was imperative that fundamental

structures of consciousness, that is to say the 'essences', were revealed (Lopez and Willis 2004; Koch 1995; Husserl 1962). Husserl (1962) believed that 'the essences' were universal to any lived experience and that they represented the true nature of the phenomenon under investigation, resulting in one correct explanation of the phenomena under investigation. Husserl thought that it was necessary to develop a rigorous, scientific foundation for the natural and human sciences and, as a result, introduced the concept of 'transcendental objectivity' (Lopez and Willis 2004). In order to achieve this, he proposed that individuals had to 'bracket' the outer world by continually assessing and 'neutralising' any biases and preconceptions that may be present (Lopez and Willis, 2004), only then could contact with the 'essences' be achieved.

IPA's claims of being a phenomenological approach have been criticised on the grounds that true phenomenological approaches should aim to bracket out preconceptions in order to view the world in a pre-cognitive state (Moustakas 1994) and that interpretation and phenomenology are not compatible. However, IPA ascribes more to the latter phenomenological works of Heidegger (1962) and Gadamer (1989).

Heidegger, a student of Husserl, revisited many of his phenomenological assumptions and based himself in the interpretive or hermeneutic research tradition (Lopez and Willis 2004). His approach, rather than focusing on the description of core essences, looked for the meanings embedded in everyday life. The aim of his form of enquiry was on experience rather than what was consciously known; it focused on the 'person and the context of their existence' (Mackey 2005). In contrast to the epistemological stance of Husserl (1962), Heidegger came from a more ontological perspective; his objective was to understand the nature of being itself and used the term 'being-in-the-world' to denote this concept (Heidegger 1962). He believed that phenomenological enquiry should focus on the relationship of the individual to his/her life 'world' and used the term 'indissoluble unity' to emphasise this concept (Heidegger 1962). Heidegger (1962) advocated that there are many ways of 'being in the world' but most important was in being aware of one's own being, that is to say, *Dasein*. To exist in this way, he believed, was to exist 'authentically' and he proposed that access to the 'lived experience' can only be achieved through exploration of this entity. He contested Husserl's phenomenology and believed that description devoid of interpretation was impossible and pioneered interpretation as both a concept and method of phenomenology (Heidegger 1962). He believed that understanding through interpretation was

meaningful and resulted in the true revelation of the phenomena (Heidegger 1962). Furthermore, in contrast to the works of Husserl (1962) and his views on 'bracketing', Heidegger (1962) believed the presence of fore-structures (for example, existing knowledge and experience) to be both useful and valuable. He used the term 'the hermeneutic circle' to illustrate the continual relationship between pre-existing knowledge and experience in understanding.

Following on from the work of Heidegger, Gadamer (1989) questioned how understanding was possible (Lavery 2003). As with his predecessor, he believed that language and understanding were inseparable features of '*being in the world*' (Lavery 2003). He viewed humans as being intrinsically historical individuals and believed that all interpretations of existence needed to be framed in terms of historical consciousness. He rejected Husserl's notion of bracketing, describing it as being '*absurd*' (Gadamer 1989:398). According to Gadamer (1989), being aware of one's own history/experiences (which he termed '*prejudices*') enables individuals to transcend to a 'fusion of horizons' (Gadamer 1989:305). Gadamer (1989) defined the '*horizon*' as '*the range of vision that includes everything that can be seen from a particular vantage point*', and utilised the term '*fusion of horizons*' to denote the dialectical interaction between the expectation of the interpreter

and the meaning of the text (Laverty 2003:10). According to Koch (1999), research grounded in the works of Gadamer aims to understand the fusion of horizons between the researcher and the participant or between the text and the person interpreting it.

Therefore, Heidegger's (1962) stance on the individual 'being in the world' and Gadamer's (1989) view on the importance of historical and socio-cultural background in shaping our perceptions of the world, support IPA's notion of seeking an 'insider's' perspective and interpretation in that it acknowledges the researcher's past and personal beliefs in the construction of knowledge (Fade 2004). IPA has also been linked to the theory of hermeneutics (interpretation) and, as has been previously inferred, plays homage to the role of the researcher in the research process (Smith et al. 2009a). It acknowledges how access to the participants' 'lived experience' is influenced by their role in the research process in that they are required to make sense of participants' accounts through a process of interpretation. IPA is said to involve a double hermeneutic in that as well as the individual attempting to make sense of their world, the researcher is, in turn, trying to make sense and interpret the accounts of the participant (Smith and Eatough 2007).

IPA has also been linked to Symbolic Interactionism (Mead 1934) which focuses on the meanings that individuals ascribe to events and how these meanings are obtained through the process of interpretation. It is interested in how meanings occur and, in turn, are made sense of, with particular interest in social interactions (Smith 1996).

IPA has been described as an idiographic mode of inquiry (Smith and Eatough 2007). In contrast to nomothetic approaches where analysis is conducted only at a group level, IPA advocates the examination of the individual case in the first instance and therefore can make claims on an individual basis. It also facilitates the analysis of individuals at a group level in order to identify shared themes that participants may have (Smith and Eatough 2007). This approach, therefore, has much affinity with Grounded Theory in that it focuses on individual cases in the first instance before integrating cases to present findings at a group level (Willig, 2001). However, both approaches, whilst having many similarities, differ in one main area: the role they give to cognitions. Whilst Grounded Theory is concerned with explicating the verbal statements of participants it does not link this to underlying cognitions and, unlike IPA, is not interested in what a participant thinks about a particular phenomenon.

4.4 Rationale for using IPA

Therefore, following a discussion on various qualitative research methodologies (Grounded Theory, Discourse Analysis), including IPA, a rationale for why IPA was selected to study the lived experience of symptom clusters in patients with cancer will be provided in the following text.

One of the main differences between the three approaches discussed is the role of cognitions. IPAs focus on the role of cognitions and how these can be inferred through the analysis of language, which allows the researcher to explore how individuals make sense of their experiences and what they think about phenomena (Smith et al. 2009a; Smith and Eatough 2007; Smith and Eatough 2006). In order to explore and understand the lived experience of symptom clusters in patients with cancer it is important that we get some insight on how people feel and think about this phenomenon and the meanings that they ascribe to it; we need to get 'an insider's perspective'. As advocated by Krishnasamy (2000), we need to explore the meanings that particular phenomenon have to the person experiencing it. Grounded Theory and Discourse Analysis do not facilitate such an exploration (Smith et al. 2009a).

As has been previously stated, some qualitative research methodologies, such as Discourse Analysis, have been criticised for their omission of extra discursive factors such as the body. IPA is a methodology which acknowledges the body and therefore can contribute to the biopsychosocial perspectives of health (Reid et al. 2005). It recognises the importance of understanding a patient's perception of, and interpretation of, their bodily experiences and the meanings which they assign them, an approach which has been neglected in the study of symptom clusters in patients with cancer to date.

The phenomenological origins of IPA and its focus on the lived experience of the person in the context of their own life (Smith et al. 2009a) has an affinity with the constructionist standpoint of the researcher and the importance of gaining knowledge in the context of the person being in the world. The hermeneutic component of IPA (Smith et al. 2009a; Smith and Eatough 2007; Smith and Eatough 2006) also identifies with this constructionist stance in viewing knowledge as a co-construction with the researcher and the participant. This is in contrast to other methodologies (for example, the non-constructionist version of Grounded Theory) which aim to minimise the role of the researcher in the process.

Finally, the idiographic focus of IPA (Smith et al. 2009a) is in contrast to the predominate nomothetic approach to the study of symptom clusters in people with cancer to date, which will facilitate an in-depth exploration of this phenomenon from the perspective of the individual. With the advocacy of patient-centred and individualised care (Olsson et al. 2009; Wolf et al. 2008) it is imperative that the experience of the phenomenon at an individual level is explored. This idiographic focus is not evident in the other approaches discussed earlier in the text.

Therefore, in conclusion, having provided justification for the qualitative exploration of symptom clusters in patients with cancer and why IPA was considered an appropriate methodology for the study of this phenomenon, the methods used in this study will now be presented.

Chapter 5 Study methods

5.1 Introduction

The previous chapter provided the justification for the qualitative exploration of symptom clusters in patients with cancer and why IPA was considered an appropriate methodology for the study of this phenomenon. This chapter of the thesis details the methods used in this study. This will include a discussion of the aims and research questions which governed this study, the sample of patients recruited to the study, the study design, methods, and data analysis strategies used to ensure that the aims of the study were met.

5.2 Aim of the study

As previously stated, the aim of this study was to explore and understand the experience of symptom clusters in patients with advanced lung cancer. In order for me to address the study aims, the following research questions were developed:

- What is the 'lived experience' of symptom clusters in patients with advanced lung cancer?
- How do people with advanced lung cancer understand and make sense of the symptom clusters that they are experiencing?

I anticipated that the first research question would allow me to address my study aims by determining the lived experience of symptom clusters in patients with advanced lung cancer. The second question would facilitate an understanding of the experience of symptom clusters in the context of the patient's life. Throughout this study, these questions were referred to frequently to ensure that the aim of this research study was being addressed. As indicated in chapter 1, for the purposes of this study a symptom cluster was defined as being the experience of three or more concurrent symptoms.

5.3 Study design

As discussed in the previous chapter pertaining to the methodology selected for this study, a qualitative, prospective study design was used. In order to test the proposed study procedures I conducted a pilot study and results of this are presented in chapter 6 of this thesis.

5.4 Patient population

5.4.1 Clinical site

The study was conducted in one clinical site in Scotland. This site was selected since it offers both inpatient and outpatient oncology

services to patients within the defined locality with over 500 patients from this site being diagnosed with lung cancer each year. This site was also selected for pragmatic reasons, as I already had an established network of health professionals to assist me in the recruitment process.

5.4.2 Sampling strategy and sample size

Criterion sampling was used to recruit patients to this study. This type of sampling is commonly used in qualitative research studies and 'fits well' with the methodological principles of an IPA study which is to explore the meaning of phenomena within the experience of the individual (Smith et al. 2009a). This type of sampling allows the researcher to 'review and study all cases that meet some pre-determined criterion' and therefore ensure that the participants recruited to the study are 'rich' with information which can be used to answer the research questions posed and address by the study aims (Patton 2002).

I planned to recruit 10 patients in total to this study. This sample size is the upper limit of the number of participants advocated for studies employing IPA (Smith et al. 2009b; Reid et al. 2005; Smith and Osborn 2004). I felt that this size of sample would allow me to

pay homage to the idiographic focus of IPA whilst allowing me to develop meaningful points of similarity and difference between the participants.

5.4.3 Selection of the sample

Studies utilising IPA typically try to find a homogenous sample for whom the research question will be meaningful (Smith et al. 2009a). Therefore, patients with advanced lung cancer experiencing multiple concurrent symptoms were selected for the study sample. This sample was selected as they are known to commonly experience multiple concurrent symptoms and have been reported to experience higher levels of symptom severity and distress compared to patients with other cancer types (Cooley 2000). Furthermore, a number of various symptom clusters had already been reported in this patient group in the literature (Wang et al. 2008; Brown et al. 2007; Fox and Lyon 2006; Wang et al. 2006; Gift et al. 2003). Details of the participants recruited to this study are presented in table 13 (chapter 7).

I did face the dilemma of deciding what criteria I could apply to ensure that the patients that I intended to recruit to the study were experiencing the phenomenon that I wanted to explore. On reading

the literature, and as highlighted in chapter 3, it had come to light that the strength of the scientific base underpinning current definitions of symptoms clusters had been criticised widely in the literature, and at the most fundamental level it had been questioned 'whether the characteristics defined in conceptual definitions' could be observed in patients with cancer (Barsevick et al. 2005). However, whilst taking the above into consideration, I also felt that I needed to have some criteria which were indicative of symptom clustering in this patient group. Therefore, I decided to use the only information which was available to me at that time, and define a symptom cluster for the purpose of this thesis as being the experience of three or more concurrent symptoms. This definition is based on existing definitions of symptom clusters in patients with cancer which purport that 'concurrence' is a core characteristic of this phenomenon (Kim et al. 2005; Dodd et al. 2001b) and where the number of symptoms thought to constitute a symptom cluster is three or more (Dodd et al. 2001a; Dodd et al. 2001b). Furthermore, the characteristic of concurrence has been used as evidence of symptom clustering in previously published qualitative studies of symptom clusters in patients with cancer (Lopez et al. 2011; Molassiotis et al. 2010; Molassiotis et al. 2008). The requirement for participants to be able to communicate in English was a pragmatic decision based on the method of data collection employed in the

study (unstructured interviews). In the likelihood of the participants being recruited to the study presenting with advanced disease, the necessity to have a life expectancy of greater than two months was selected to facilitate the objectives of the study and minimise attrition rates which are known to be high in this patient group (McMillan and Weitzner 2003). The decision not to allow participants with a diagnosis of any other type of cancer was made in order to maintain the homogeneity of the study sample. A table of the inclusion and exclusion criteria for this study are detailed in table 5 below.

Table 5: Details of inclusion and exclusion criteria	
Inclusion criteria	Exclusion criteria
Aware of a diagnosis of lung cancer	A diagnosis of any other type of cancer
Experiencing multiple concurrent symptoms (three or more)	Unable to meet any of the inclusion criteria
Able to communicate in English verbally	
Life expectancy of greater than two months	
Deemed physically and psychologically fit to participate by any member of the healthcare team	
Able to give written, informed consent	

5.4.4 Process of recruitment

The process of recruitment was guided by discussions with clinical collaborators at the clinical site and in line with ethical recommendations (see section 5.4.5). Eligible participants were identified by the Lead Nurse for Lung Cancer based at the participating hospital, who provided them with both verbal and written information about the study (see appendix 1). If the patient was interested in participating in the study, the Lead Nurse for Lung Cancer asked them to sign a form, authorising him to pass on their personal contact details to the researcher (see appendix 2).

Following a period of no less than 72 hours, the researcher then contacted the patients, explained the study, answered any questions and asked them if they would like to take part in the study. If the participant did wish to take part in the study, a mutually suitable date, time and place was organised for the patient and the researcher to meet in order to obtain written informed consent and to conduct the first interview (see appendix 3). All patients who were contacted by the researcher agreed to take part in the study. Patients were also reminded that they could withdraw from the study at any time without their treatment and care being affected in any way.

5.4.5 Ethical considerations

Ethical approval was granted by the Local Ethics Committee in December 2006. There were a number of ethical considerations that I had to address prior to and throughout this research study. These issues were addressed using Beauchamp and Childress's (2001) principles of biomedical ethics as a framework. This included respect for autonomy, beneficence and non-maleficence, and justice. Each of these considerations will be discussed in turn below.

5.4.5.1 Respect for autonomy

Respect for autonomy acknowledges a person's right to make decisions and take actions based on their own values and beliefs. It means not interfering with other people's choices and ensuring they are free from coercion regarding any decision that they make (Beauchamp and Childress 2001).

In this study, I ensured that the participants' autonomy was protected by gaining written, informed consent. This included ensuring that the participants knew that it was their decision on whether or not they participated in the study and that if they decided not to take part, their care and treatment would not be affected in any way. I also ensured that they were provided with adequate

information, both verbally and in writing, to make certain that their decision on whether or not to participate in the study was based on an appropriate understanding of the study and the expected benefits, burdens, risks and reasonable alternatives.

Autonomy was also protected in the interview process telling the participants at the start of the interviews that they did not have to answer a question if they did not want to, that they could stop the interview at any time and that they were free to withdraw from the study at any point if they wished. Participant autonomy was also preserved by the use of unstructured interviews which allowed the participants to set their own agenda and determine what issues they wanted to talk about in their interviews. Furthermore, prior to the second interview, the participants were once again asked if they were happy to be interviewed, reminded that their participation was entirely voluntary, and that they could withdraw at any time.

5.4.5.2 *Beneficence and non-maleficance*

These terms denote balancing the benefits of participating in the study to the potential harm (Beauchamp and Childress 2001). As with respect for autonomy, adherence to this issue was ensured by providing patients with both verbal and written information of the

benefits and risks pertaining to their involvement in the study. Issues regarding the beneficence and non-maleficence of the study were also apparent in relation to the interview process. When planning my study, I was concerned that the participants would become upset and distressed during their interviews when talking about sensitive topics, particularly in light of the unstructured approach that I proposed to use. Whilst it was not my intention to cause any level of distress to the participants, I felt that I had to make sure that my research plan had addressed these issues to ensure patient wellbeing throughout their participation in the study.

Therefore, I employed a number of measures to ensure that issues such as beneficence and non-maleficence were being addressed. At the start of the study, I reinforced the information already provided in the patient information sheet regarding the risk of them becoming upset during their interviews when discussing topics of a sensitive nature. I told them that in such circumstances they could suspend or terminate the interview if they wished, and that if they decided to undertake any of the above, then their care and treatment would not be affected in any way. In addition, throughout the interviews, particularly at times when the participants talked about sensitive topics, I frequently asked them if they were happy to talk more on the subject, asking them to give me reaffirmation that they

consented to the interview process throughout and that they were happy to talk about the topics at hand. Whilst being offered this option on several occasions throughout both interviews, no participant declined to talk about a topic when further questioned. At the end of each interview, I also asked each of the participants what they felt about their experience of being interviewed, and all stated that they viewed it as being a positive experience and found it beneficial to talk to someone about their illness who was not immediately involved in their family/social circle or medical care. I also gave them a card for a recognised cancer charity confidential helpline with a contact number on it to use if they became upset about any of the issues that they had discussed.

In ensuring no harm to the participants involved in this study, I also had to ensure that all documentation, reports and publications relating to the study were in accordance with the regulations set out in the Data Protection Act (1989). It was essential to ensure that no patient identifiers were detailed on any of the study documentation. This was achieved by giving all patients who consented to the study a unique study number from which patients could not be identified by anyone other than the researcher. Anonymity in the participants' transcripts was ensured by eradicating any names and identifiable data, and replacing all names with pseudonyms. Furthermore, it was

important to ensure that personal details were stored securely in a locked filing cabinet which could not be accessed by anyone other than the researcher. Throughout the research process the participants were assured that their responses were confidential and that their anonymity would be protected. According to University of Stirling regulations, data collected during the study will be archived for ten years.

5.4.5.3 Justice

The term 'justice' refers to the human regard for fairness, and for everyone to be given the same chance to take part in research studies (Beauchamp and Childress 2001). Adherence to this principle was maintained by ensuring that all eligible patients were invited to participate in the study. Issues such as 'gatekeeping' by health professionals could have potentially impacted on the adherence to this ethical principle, however in this study gatekeeping was not an issue. This may have been due to the close collaboration between myself and the clinical team and the mutual belief in the potential benefit of the study in patients with lung cancer. Having discussed the ethical issues pertaining to this study, the following section will detail the data collection methods employed in this study.

5.5 Data Collection

The aim of this study was to explore and understand the experience of symptom clusters in patients with advanced lung cancer. In order to meet this aim, the methods that I adopted had to facilitate the collection of data which would provide an 'insider's' perspective of this phenomenon and give experience a central position whilst recognising the multiple factors that can influence such experience. The use of in-depth interviews appeared to be a method which would allow me to collect such data and address the aims of the research posed. A key feature of this type of method of data collection is its in-depth of focus on the individual (Ritchie and Lewis 2006). It has been described by Ritchie and Lewis (2006) as being:

The only way to collect data where it is important to set the perspectives heard within the context of personal history or experience; where delicate or complex issues need to be explored at a detailed level, or where it is important to relate different issues to individual personal circumstances' (Ritchie and Lewis 2006:58)

Other methods of data collection have been used in IPA studies such as focus groups (Dunne and Quayle 2001; Flowers et al. 2001), observational notes (Larkin and Griffiths 2002), diaries (Smith 1999), and e-mail (Murray and Harrison 2004). However, these methods of data collection were not selected as I felt they did not pay homage to

the idiographic focus of IPA methodology (focus groups), would not facilitate the collection of in-depth data that I required to answer my research questions (observational notes), and were not appropriate for use in the patient population that I intended to recruit, who were patients with advanced lung cancer, many of whom would be frail and nearing the end of life (e-mail).

5.5.1 Semi-structured or unstructured interviews?

Having decided to use in-depth interviews as my method of data collection, I then had to determine what type of in-depth interview technique to use. Within qualitative research there are predominantly two types of interviews which are used: the semi-structured interview, and the unstructured interview. Each type of interview produces different data and should be selected based on the aim of the study and the research questions posed.

In the semi-structured interview, the questions asked by the researcher function as prompts that encourage the participant to talk and it is these questions which direct the interview and type of data collected, in order to answer the research questions posed (Willig 2001). In comparison, in the unstructured interview, only one question is asked at the beginning of the interview and the way that

the interview transpires is entirely dependent on how the participants reply to the first question (Smith et al. 2009a). This type of interview is commonly used when there is not a lot known about the topic under study and is central to specific methodologies, such as IPA, where the researcher aims to explore the meaning or essence of the phenomenon being investigated (Smith et al. 2009a; Smith 1996). According to Smith et al (2009a), this method of interviewing attempts to 'implement IPA's inductive epistemology to the fullest extent' and 'facilitates an appreciation of the participants' priorities' (2009a:70).

In relation to the current study, I was aware that most IPA studies published in the literature had used semi-structured interviews (Smith and Eatough 2007) and that this type of interview was viewed as being an exemplary method of data collection for this selected methodology (Smith 2004). However, as the aim of my study was to explore the experience of symptom clusters in patients with advanced lung cancer, I felt that it was imperative that I captured the patient's (not my) perspective of this phenomenon. I wanted to acknowledge the patient as being the 'experiential expert' to bring to the fore issues which were important to them relative to the experience of symptom clusters in the context of their lives (Smith et al. 2009a; Corbin and Morse 2003). Furthermore, in line with my

epistemological stance, being a contextual constructionist, I also wanted to ensure that I captured the context of the experience of symptom clusters, as I viewed this as being a crucial element to my understanding of this phenomenon in patients with advanced lung cancer.

Therefore I chose to use unstructured interviews which I felt would allow the participants the space and the opportunity to spontaneously talk about issues which they deemed to important and meaningful within their lives, before probing and focusing the discussion on the experience of symptom clusters. I felt that this approach would facilitate an inductive bottom-up generation of data relating to symptom clusters (as the principle means to understand how they are experienced within the context of peoples' lives) and prevent me from prematurely/forcefully go in fishing for the concepts immediately. Therefore the unstructured interview appeared to be the most suitable method in which to achieve these objectives.

5.5.2 Details of interviews

5.5.2.1 Number and timing of interviews

Having decided on an unstructured interview approach for the study, I then had to consider the number and timing of the interviews that I

proposed to conduct. When addressing these issues I had to take into consideration not only the study aims and research questions that I had to answer, but also the patient sample that I intended to recruit. I had decided to conduct the study in patients with advanced lung cancer. Taking into consideration that the majority of patients with lung cancer present with advanced disease (Corner et al. 2005), and from previous clinical experience working with this patient group, I knew that many of the participants recruited to the study would be frail, experiencing a high symptom burden and nearing the end of life. Therefore, I felt that asking them to participate in one in-depth interview that could potentially last for two hours may be too onerous for them and therefore ran the risk of the interview being terminated early. I therefore decided that in order for me answer my research questions and gain an in-depth exploration of the participants' experiences, whilst at the same time addressing issues such as participant burden, that I would conduct two interviews with the participants, 3-5 weeks apart. As stated by Flowers (2008:25), the use of multiple interviews *'may relate to "pragmatic" concerns. These may include, for example, participant characteristics such as their availability, health (e.g. people with respiratory conditions), or "attentional capacity" (e.g. children)'*. This approach to interviewing has also been advocated for use in patients with progressive diseases and, as stated by Murray and Sheik (2006):

A single interview or focus group, especially with ill people, might be inadequate to fully explore issues, especially if addressing a sensitive or complex area. Returning for further rounds of data collections, not only allows participants to disclose information at their own pace, but also permits trust, empathy and a deeper understanding to emerge (Murray and Sheikh 2006:901).

Furthermore, this approach to interviewing had previously been used in studies utilising IPA (Flowers 2008; Dickson et al. 2008; Smith 1999).

The timing between interviews was selected to facilitate an iterative approach between the first and second interview (detailed in the following section) without unduly burdening the patient and in light of the high levels of attrition commonly reported in this patient group (Sherman et al. 2005; Murray et al. 2004).

5.5.2.2 *Setting of interviews*

The setting for the interviews was determined jointly by myself and the participants. I provided them with the option of being interviewed at home or in a quiet room in the hospital.

5.5.2.3 Interview schedule

As stated above, unstructured interviews were selected as the method of data collection for this study. In this type of interview, the researcher traditionally starts with a single core question which then directs the rest of the interview (Smith et al. 2009a). According to Smith et al. (2009a), IPA studies 'attempt at the research question "sideways"'. This occurs because most research questions are situated at an abstract level, which are not suitable to be posed directly to the patient. Instead, interview questions are developed to facilitate the discussion of relevant topics which will allow the research question to be answered.

I therefore decided to start the first interview with each of the participants by asking 'What does cancer mean to you?' This question was selected in light of the core role that meaning plays in the illness experience (Thorne 1999; Johnson Taylor 1995; O'Connor et al. 1990; Kleinman 1988a; Good and Good 1980; Mishler 1979; Frankl 1959), with particular relevance to the symptom experience (Krishnasamy 2000; Ferrell and Dean 1995; Kleinman 1988a; Good and Good 1980). It was anticipated that asking this question would facilitate the open the discussion of relevant topics with an appreciation of the participants' priorities, to allow the aims and objectives of the study to be met.

The participants' response to this initial question posed in the first interview was viewed as reflecting an overall summary of what they wished to talk about and was used to set a participant-led agenda. I therefore returned to each issue in turn, probing downwards from the general to the specific. The interview was facilitated by me reflecting and probing, asking questions such as 'Can you tell me more about that?', 'What were you thinking at the time?', and 'How did you feel about that?'. My main role in the interview process was to stimulate discussion and allow the participant to talk freely and comfortably about their experiences.

Taking into consideration the iterative approach adopted by the study, the aim of the second interview was to explore in more detail some of the issues that were not probed in the first interview, in order to clarify details and to ask new questions based on close reading of the first interview transcript. I therefore started the second interview by asking 'Is there anything from our last interview that you would like to talk about?' Once again I used the same probing techniques. I used verbatim quotes from the first interview when asking participants to elaborate on a topic previously discussed. Using this format, the aims of the second interview did appear to be met allowing more in-depth exploration of points that had been

previously raised and the uncovering of 'new' issues which were not discussed in the first interview.

All interviews were recorded following consent being provided by the participants at the start of each interview. Following each interview, field notes and reflexive accounts were maintained to assist in any subsequent interviews and data analysis. The interviews were transcribed verbatim by one of the members of the study support team. I checked each transcript with the digital recordings to ensure that all the information had been recorded correctly and made some minor modifications to them where required. I securely stored all recordings and transcripts in a locked filing cabinet.

5.6 Data Analysis

'The essence of IPA lies in its analytic focus' which is to direct 'our analytic attention towards our participants' attempt to make sense of their experiences' (Smith et al. 2009a:77). According to Smith and Osborn (2003:66), 'meaning is central to that experience and the aim of the analysis is to try to understand the content and complexity of those meanings'. They also point out that such meanings are not 'transparently available' but must be reached through sustained

engagement with the text and the process of interpretation (Smith and Osborn 2003:66).

The step-by-step approach to analysis advocated by Smith and Osborn (2003) was used to analyse the data. The procedure which I adopted in this study involved treating the two interviews for each participant (where available) as one set of data. In brief, the analytical stages included: reading and re-reading of the interview transcripts; initial noting; development of emerging themes; searching for connections amongst emergent themes; moving to the next case; and looking for patterns across cases. This procedure was not designed to be used in a linear manner, but to be applied flexibly according to the analytic task at hand. Each point in the process of analysis is detailed below with exemplars from Dan's transcripts to illustrate each process and to illustrate the procedures followed.

5.6.1 Reading and re-reading of the interview transcripts

This is the first step in the process of data analysis and is used to immerse the researcher in the data so that the participant becomes the focus of the analysis (Smith et al. 2009a; Smith and Osborn 2003). I therefore read each transcript several times, aware that each reading had the potential to offer me new insights into the data.

On two occasions whilst reading the transcripts I also listened to the audio recording at the same time, as this allowed me to re-familiarise myself with the participants and their accounts. With each reading, I became more immersed in the data, uncovering new issues and becoming more receptive to what was said by the participants. During this time I made some notes I thought may be useful to return to at a later date, to check against any interpretations that I had made.

5.6.2 Initial noting

This part of the analytical process assists the researcher in becoming familiar with the text and to start to identify the ways in which the participants talk about, understand and think about issues they have raised (Smith et al. 2009a; Smith and Osborn 2003). Therefore, having read the transcripts on several occasions, I started to record anything that I thought was interesting and/or significant in the left-hand margin. This process is illustrated in the following excerpt from Dan (see Table 6 below).

Table 6: Initial noting

Exploratory comments	Original Transcript (Dan, page 12-13, interview 2)
<p>Breathing again – blames this solely on his condition worsening – scared that he was going to die – once again link with breathlessness and death. Very important as he spontaneously talks about this symptom</p> <p>Positive thinking – feels that this has some therapeutic benefit – see previous quote in interview</p> <p>Breathing getting to him – sense he feels that he cannot tolerate it anymore</p> <p>Links breathlessness with feeling low</p> <p>Breathing affecting him – scared that it will come to a point when they can no longer treat his breathlessness – feels at this point death will be very near – afraid of this</p> <p>Comes to this point – jokes he would commit suicide – but then states that he is jesting – shows how significant this symptom is to him</p> <p>Uses humour a lot when talking about issues which he finds upsetting – coping with fear of death</p> <p>Changes subject – talks about how he needs</p>	<p>DAN: ... you get into it, y., y., y., as I said I was going doon, the breathing was getting to me and I was gradually sliding the wrong way, I'm usually sliding – "uphill" but wi' the breathing getting tae me I was sliding doon hill, but I was feart I was going to slide too far doonhill, you know what I mean</p> <p>ROMA Can you tell me a wee bit more ...about...</p> <p>DAN: Well eh, during the xx [name of nurse] and ?????? and aw that says it was your attitude, your approach that's kept you up you know eh, and with this breathing getting to me and so...[makes gasping sound] it does get you down, you say to yoursel, and what and, and they'll say to you, we'll maybe no can dae much fur yae em, its just through the illness and your saying to yourself, Jesus Christ if that's the case I'll jump oaf ... I know that I'm telling it to you, but I don't really mean it, I'll jump oaf a brig and dae away wi' masel then you know, rather than this hinging our yae and, and I said the other day...and I got for my last chemo this week, next week, I says to her what happens efter that wi' the breathing, I says do I get a Calor Gas can tied tae my back, ken [cracks joke], I'm still joking about it like, you know but, seriously deep down it is very serious like you know em, but you've goat tae keep your pecker up by joking about things like, you know because</p>

<p>humour to cope with what his happening to him</p> <p>Social comparison – coping – others who are worse than him</p> <p>All that matters to him is that he is still breathing – still alive – is this at whatever cost?</p> <p>Value of life – just being alive is good enough for him – does quality matter to him?</p> <p>Comfort that the consultant told him that his is like everyone else – no one really knows what the future holds....</p> <p>Body – he will know when he is at that stage- his body will tell him – once again uses the body as a gauge in determining how he is</p>	<p>if everybody was dull in doldrum, the world would be a hellish place, you've goat to have a bit of laughter in life and your actually make, your basically keeping your ain perk up by making a joke by saying, well I don't want a hose stuck up my nose, kind of thing like you know ... [laughs], you know he was like that [demonstrates], ?????????????????????? [29.09] because actually your making a joke regarding yourself, I've, I've seen other folk oh my god... you feel very sorry for people....it's a way oh life ... em, if you have to get it, you've to get it ... it's the only way to walk one fit in front oh the other then you dae it ... and folk's say to me, how are you this morning, I'll say fine .. eh, aye no bad I says, how are you, ah nae use oh complaining, naebody listens like you know or eh, och I walk along the road and I'm still breathing, so I take it I'm still here like, you know, just ... you know somebody said to me, I says well I walk some other ??????? how are you this morning? I says I woke up this morning and I'm still here, so ... another day ... and that's the way I've looked at it, throughout. Its no until I wake up in the morning and I'm still breathing, I'm still here, the mans daing his joab, he's keeping me alive [laughs] and hopefully he'll keep me alive a long while. Because as I said to you the last time, I asked him one day outright, I says how long has I got to go?, he says how long have I got, he says eh, I could jump in front of a bus the morn and be deed, I says well that is very true, but the ?????????????????????? I could jump in front oh a bus the morn tae mate, the man cannae answer the question. OK when you, possibly when you get further doon the line and your really in a state they can say well you've got X amount of months, years, days, weeks, but your really doon, by that time you know yoursel, cause its you should know yerself [laughs] eh, and naw they don't, they're doing their job, like everybody else... to the best of their ability, you know I admire them for it</p>
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5.6.3 Looking for themes in the first case

This stage of the analysis involves looking for emergent themes from the data by observing the relationships, connections and patterns between the exploratory codes. This process involves a shift in the researcher's focus from the original transcripts to the exploratory coding, in an attempt to reduce the volume of data whilst at the same time maintaining the essence of what the participant has said (Smith et al. 2009a; Smith and Osborn 2003).

I therefore viewed the exploratory codes that I made in the left hand margins of the transcripts, and attempted to capture what was represented in the text through the use of thematic labels. These labels were inserted in the right-hand margin of the text. I was thorough in this process to ensure the thematic labels developed were grounded in the data. This process is illustrated in the same quote by Dan used above. It demonstrates how I moved from the initial codes to the development of thematic labels (see Table 7 below).

Table 7: Looking for themes in the first case

Exploratory comments	Original Transcript (Dan, page 12-13, interview 2)	Emergent Themes
<p>Breathing again – blames this solely on his condition worsening – scared that he was going to die – once again link with breathlessness and death. Very important as he spontaneously talks about this symptom</p> <p>Positive thinking – feels that this has some therapeutic benefit – see previous quote in interview</p> <p>Breathing getting to him – sense he feels that he cannot tolerate it anymore</p> <p>Links breathlessness with feeling low</p> <p>Breathing affecting him – scared that it will come to a point when they can no longer treat his breathlessness – feels at this point death will</p>	<p>DAN: ... you get into it, y., y., y., as I said I was going doon, the breathing was getting to me and I was gradually sliding the wrong way, I'm usually sliding – “uphill” but wi' the breathing getting tae me I was sliding doon hill, but I was feart I was going to slide too far doonhill, you know what I mean</p> <p>ROMA Can you tell me a wee bit more ...about...</p> <p>DAN: Well eh, during the xx [name of nurse] and and aw that says it was your attitude, your approach that's kept you up you know eh, and with this breathing getting to me and so...[makes gasping sound] it does get you down, you say to yoursel, and what and, and they'll say to you, we'll maybe no can dae much fur yae em, its just through the illness and your saying to yourself, Jesus Christ if that's the case I'll jump oaf ... I know that I'm telling it to you, but I don't really mean it, I'll jump oaf a brig and dae away wi' masel then you know, rather than this hinging our yae and, and I said the other day...and I got for my last chemo this week, next week, I says to her what happens efter that wi' the breathing, I says do I get a Calor Gas can tied tae my</p>	<p>Breathlessness- salient symptom – links to prognosis</p> <p>Coping –positive attitude</p> <p>Breathlessness – salient – fear of death</p>

<p>be very near – afraid of this</p> <p>Comes to this point – jokes he would commit suicide – but then states that he is jesting – shows how significant this symptom is to him</p> <p>Uses humour a lot when talking about issues which he finds upsetting – coping with fear of death</p> <p>Changes subject – talks about how he needs humour to cope with what his happening to him</p> <p>Social comparison – coping – others who are worse than him</p> <p>All that matters to him is that he is still breathing – still alive – is this at whatever cost?</p> <p>Value of life – just being alive is good enough for him – does quality matter to him?</p>	<p>back, ken [cracks joke], I'm still joking about it like, you know but, seriously deep down it is very serious like you know em, but you've goat tae keep your pecker up by joking about things like, you know because if everybody was dull in doldrum, the world would be a hellish place, you've goat to have a bit of laughter in life and your actually make, your basically keeping your ain perk up by making a joke by saying, well I don't want a hose stuck up my nose, kind of thing like you know ... [laughs], you know he was like that [demonstrates], ?????????????????????????? [29.09] because actually your making a joke regarding yourself, ...</p> <p>I've, I've seen other folk oh my god... you feel very sorry for people....it's a way oh life ... em, if you have to get it, you've to get it ... it's the only way to walk one fit in front oh the other then you dae it ... and folk's say to me, how are you this morning, I'll say fine .. eh, aye no bad I says, how are you, ah nae use oh complaining, naebody listens like you know or eh, och I walk along the road and I'm still breathing, so I take it I'm still here like, you know, just ... you know somebody said to me, I says well I walk some other ??????? how are you this morning? I says I woke up this morning and I'm still here, so ... another day ... and that's the way I've looked at it, throughout. Its no until I wake up in the morning and I'm still breathing, I'm still here, the mans daing his</p>	<p>Humour - coping</p> <p>Social comparison - coping</p> <p>Breathlessness – salient – need to breathe to live</p> <p>Social comparison - coping</p>
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<p>Comfort that the consultant told him that his is like everyone else – no one really knows what the future holds....</p> <p>Body – he will know when he is at that stage- his body will tell him – once again uses the body as a gauge in determining how he is</p>	<p>joab, he's keeping me alive [laughs] and hopefully he'll keep me alive a long while. Because as I said to you the last time, I asked him one day outright, I says how long has I got to go?, he says how long have I got, he says eh, I could jump in front of a bus the morn and be deed, I says well that is very true, but the ?????????????????????? I could jump in front oh a bus the morn tae mate, the man cannae answer the question. OK when you, possibly when you get further doon the line and your really in a state they can say well you've got X amount of months, years, days, weeks, but your really doon, by that time you know yoursel, cause its you should know yerself [laughs] eh, and naw they don't, they're doing their job, like everybody else... to the best of their ability, you know I admire them for it</p>	<p>Reliance on health professionals to live</p>
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Once I had identified the thematic labels I then looked for connections between the emergent themes. I did this by typing all the themes in chronological order into a list and then tried to identify patterns between them which would lead to the development of a super-ordinate theme. Smith (2004:71) has described this process like being a magnet 'with some of the themes pulling others in and helping make sense of them'. He also points out that in this stage of the analysis some of the themes may not be used because they do not fit with the emerging structure or because they have a weak evidential base. At the end of this process a table is produced which illustrates each super-ordinate theme and the themes which comprise it. Smith and Eatough (2007) state that if the researcher has been successful in this process '*it should be possible for someone else to track the analytic journey from the raw data through to the end of the table*' (Smith and Eatough 2007:48). Therefore, in order to allow reader to track this process, a super-ordinate theme ('Fear of Death') and related sub-themes are illustrated in table 8.

Table 8: Super-ordinate Theme of 'Fear of death' and related sub-themes
FEAR OF DEATH
Symptom Clusters- threat of death nearing
Coping with fear of death
Reliance of health professionals and treatment to live

This process continued until a full table detailing each super-ordinate theme and emergent themes informing them had been made. An example of the super-ordinate themes derived for Dan is provided in table 9.

Table 9: Super-ordinate themes for Dan	
Super-ordinate themes	Sub-themes
Symptom Clusters	Linking up symptoms Finding out the cause of symptoms Salient symptom
Meaning of cancer	Bad Disease
Fear of Death	Symptom Clusters- threat of death nearing Coping with fear of death Reliance of health professionals and treatment to live
Loss of sense of self	Symptoms and being unable to do everyday things Being a burden
Stigma	Childhood experiences of cancer Symptoms and stigma
Coping	Minimising symptoms Normality Positive attitude Humour Work Social Comparison

Only after gestalt (Smith et al. 2009a) was reached for each individual case was a cross-case analysis conducted. I did this by laying out each table of super-ordinate themes for each participant side by side and looked across them for the recurrence of themes. Following guidance by Smith et al (2009a), if a recurrent theme was present in over half the sample then it was deemed to be a super-ordinate theme for the entire data set. This process is exemplified in table 10 below.

Table 10: Identifying recurrent themes (Y=Yes, N=No)											
Super-ordinate themes/ sub-themes	Emily	Veronica	Flora	Dan	Paul	Thomas	Jessie	Suzie	Richard	Ruby	Present ≥50% of sample?
The lived experience of symptom clusters and the role of context and meaning	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
The experience of symptom clusters	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Death	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Stigma	Y	Y	N	Y	N	Y	Y	Y	N	N	Y
Symptom clusters and loss of sense of self	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
The impact of symptom clusters on the self	Y	Y	Y	Y	N	Y	Y	Y	Y	N	Y
Being a burden	Y	Y	N	Y	N	Y	Y	Y	Y	N	Y
Trying to maintain a coherent and valued self	Y	Y	Y	Y	Y	N	Y	Y	Y	N	Y

5.7 Reflexivity

Interpretive phenomenological analysis 'emphasizes that the research exercise is a dynamic process with an active role for the researcher in that process' (Smith and Eatough 2006). It aims to see things from an 'insider's perspective', with the role of the researcher on this process being emphasised by using their own conceptions to understand/make sense of the participants' experiences through the process of interpretation (Smith and Eatough 2006). Furthermore, within qualitative research there has been a call for researchers to be more reflexive about their impact on the research process in order to 'enhance the credibility of their findings by accounting for the researcher's values, beliefs, knowledge and biases' (Cutcliffe 2003:137) .

Therefore, throughout the study I maintained a reflexive journal (see appendix 4) which included personal reflections and a log for methodological decisions and accompanying rationales as advocated by Lincoln and Guba (1985). Findings pertaining to my personal reflections on my experience of conducting the study interviews and study methods are detailed in Chapter 6 (section 6.2.3.6) where I discuss the conduct and findings of the pilot study. This section details how I struggled with the duality of the nurse researcher role,

particularly at times when the participants became upset during their interviews. It also details my thoughts regarding methods used and their suitability in addressing the research questions posed.

5.8 Assessing validity

The validity and quality of the study was evaluated using the criteria developed by Yardley (2000) which have been advocated for use in studies employing IPA (Smith et al. 2009a). These criteria are described under four broad headings: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. Each of these criteria will be presented below with details on how they were met in this study.

5.8.1 Sensitivity to context

Yardley argues that a good qualitative study will have demonstrated sensitivity to context. This principle was demonstrated in this study in a number of ways. The selection of IPA in itself was a way of demonstrating sensitivity to context as this methodology is influenced by a contextual constructionist stance (Willig 2001) and pays homage to context throughout all stages of the research process. Sensitivity to context was also demonstrated by the literature review conducted

for this study, which assisted in the orientation of the study and, as will be demonstrated, related to the discussion of the findings.

5.8.2 Commitment and rigour

Yardley's (2000) second criterion is 'commitment and rigour'. Commitment, both personally and professionally, was demonstrated throughout the entire research process from the inception of the topic to the writing up of the findings. This principle was of particular relevance during the data collection phase and the analysis of the data, where attentiveness to the participant was paramount. Rigour, which refers to the thoroughness of the study, was demonstrated by ensuring that the study sample was appropriate to answer the research questions posed and address the aim of this study. Rigour was also demonstrated in the quality of the interviews conducted and the completeness of the analysis undertaken.

5.8.3 Transparency and coherence

The third criterion offered by Yardley (2000) is 'transparency and coherence'. Transparency was demonstrated by clearly detailing each stage of the research process including a description of how the participants were selected, how the interview was constructed and conducted, and what procedures were followed to analyse the data.

Coherence was verified by providing a coherent argument throughout this thesis. It was also demonstrated by ensuring that each stage of the study was consistent with the methodology selected (IPA).

5.8.4 Impact and importance

The final criterion set by Yardley (2000) is 'impact and importance'. She states that no matter how well a research study is carried out, the main test of its validity is whether the findings report something that is interesting, important or useful. This principle is demonstrated in the findings of this study, which open up novel avenues for the study of symptom clusters in patients with cancer.

This chapter has detailed the methods selected for this study, including a discussion on the aims of the study, the design of the study, the study sample, methods of data collection and analytic strategies used to ensure that research questions were answered and the aims met. The following chapter will discuss the conduct and findings from the pilot study and the subsequent modifications made in preparation for the main study.

Chapter 6 Pilot Study

6.1 Introduction

A pilot study was conducted before the main study as it is an important stage of the research process (van Teijlingen and Hundley 2002). It allows the researcher to test the proposed study design and procedures, identifying areas where the main research project may require modification. A pilot study was therefore undertaken to allow the researcher to reflect on multiple aspects of the research process. The aims of this pilot study were to:

- Assess the likely success of the proposed recruitment approaches
- Assess the proposed data collection techniques
- Assess the proposed data analysis techniques
- Train the researcher in as many aspects of the research process as possible

This chapter discusses the pilot phase and issues raised in relation to its aims.

6.2 Conduct of the pilot study

The pilot study was conducted at one clinical site in Scotland over a three-month period between January and March 2007. Ethical approval was granted from the local ethics committee for both phases of this study (pilot and main). A total of three participants were recruited to the pilot study and all the participants were subject to the study procedures outlined in chapter 5 of this thesis.

6.2.1 Population

Three participants were recruited to the pilot study. Table 11 below highlights the demographic characteristics of this group. Data on the occupation, educational level and ethnicity of the participants were not formally collected in this study and therefore are not detailed in table 11.

Table 11: Demographic characteristics of the pilot phase sample	
Patients in sample (n=3)	
Age (mean)	63 years
30-39 years	0
40-49 years	0
50-59 years	0
60-69 years	1
70-79 years	2
Gender	
Male	0
Female	3
Stage of disease (TNM)	
IIIa	0
IIIb	3
IV	

All participants in the study sample were female and of similar age and all had advanced disease. This pilot sample was atypical of the characteristics expected to be observed in this patient group on the grounds of gender. Lung cancer commonly affects more men than women, with the most current reported ratio being 4:3 (Office for National Statistics 2010; ISD 2010; Welsh Cancer Intelligence and Surveillance Unit 2010; Northern Ireland Cancer Registry 2010). Therefore, the absence of males within the pilot study sample was unusual and precluded the identification of the perceptions of both

men and women on the feasibility and acceptability of the methods used. This observation is discussed further in section 6.2.2, which discusses issues regarding recruitment.

6.2.2 Recruitment process and study sample

The importance of pilot testing approaches to recruitment has been advocated by van Teijleingen and Hundley (2002). As outlined in chapter 5, eligible participants were identified by the Lead Nurse for Lung Cancer at the participating site, who provided them with both verbal and written information about the study. If the patient was interested in participating in the study, the Lead Nurse for Lung Cancer asked them to sign a form, authorising him to pass on their personal contact details to the researcher. Following a period of no less than 72 hours, I then contacted the patients, explained the study, answered any questions and asked them if they would like to take part in the study. If the participant did wish to take part in the study, I arranged a mutually suitable date, time and place to meet with the patient in order to obtain written informed consent and to conduct the first interview.

Discussions with collaborators at the clinical site indicated that on average 500 new patients were diagnosed with lung cancer each year

and therefore, based on these figures, I did not anticipate any problems regarding recruitment. Throughout the pilot study all three participants were recruited over a 6-week period, indicating that the availability of eligible participants to take part in the study would not be an issue in the main study. However, as presented in section 6.2.1, the sample that I recruited to the study in the pilot phase were all female, and I therefore had to find out why this happened and if there was any valid reason for me to change my recruitment criteria and/or procedures.

I therefore discussed the recruitment procedures with the Lead Nurse for Lung Cancer to further examine who had been approached, and reasons, if any, for their refusal to participate. I was informed that of the two men who were approached and asked if they would like to participate in the study, one felt that he was not well enough to participate and the other did not want to talk about his experiences since diagnosis. Such findings have been reported elsewhere in the literature pertaining to the recruitment of patients with advanced cancer to research trials (Sherman et al. 2005; Cooley et al. 2003a). However, whilst recognising the added value in exploring the experiences of both male and female participants with advanced lung cancer, I felt that to try and stratify the study sample was not appropriate in light of the qualitative paradigm informing the study

and the selected methodology (IPA). As Smith and colleagues (2009a) state, '*sampling must be consistent with the qualitative paradigm*' and the '*participants grant us access to a particular perspective on the phenomenon under study*', that is, they '*represent a perspective rather than a population*' (Smith et al. 2009a). Therefore, whilst acknowledging that the results of this pilot study did not represent the perceptions and views of any male participants, it was decided that the criteria for sampling adopted in the pilot study would be maintained throughout the main study.

6.2.3 Interviews

6.2.3.1 *Timing of interviews*

As described in chapter 5, interviews were conducted with the participants at two time points: on recruitment to the study, and three to five weeks later. This timing of interviews was selected in order to meet the aim of this study but without unduly burdening the patient. All participants were interviewed three weeks apart, with the exception of the first participant who died before the subsequent interview could be conducted.

Following the conducting of the interviews I then reflected on the process to determine whether any changes should be made to the ensuing main study. The timing of the interviews did appear to facilitate the iterative approach intended with all of the participants taking part in the second interview being able to clearly recall what they had discussed in the previous interview and being able to elaborate on any points that were raised. However, one issue that came to light in relation to the timing of the interviews was the time taken for the transcriptions to be typed with some being transcribed only a few days before the second interview. This left the researcher with little time to prepare for the second interview and identify areas from the first interview which warranted further exploration. However, as the timing of the interviews did facilitate and meet the study objectives, it was felt that this aspect of the interview process should remain unchanged and that added administrative support would be accessed where possible to facilitate the typing of the transcripts throughout the main study.

The issue of attrition was also highlighted in the pilot study with the first participant dying before the second interview could be conducted. This issue is not new to research in people with advanced cancer and has been widely reported in the literature (Harris et al. 2008). Changing the timing of the interviews to minimise levels of

attrition throughout the study was therefore declined as this is a recognised factor when conducting research in people with advanced cancer. Furthermore, in light of the study sample, it was thought that reducing the time period between interviews may have resulted in high levels of participant burden.

6.2.3.2 *Setting of interviews*

The setting for the interviews was jointly determined by the researcher and participants. The majority of participants were interviewed in their own homes, with the exception of one lady where her first interview was conducted within a quiet room in the hospital due to a previous in-patient admission.

The interview setting did appear to meet the study requirements by providing participants with a place where they felt free to express and share their experiences with the researcher. However, within the hospital environment there were numerous interruptions, with staff accessing the room for equipment, which did interrupt the flow of the interview on a few occasions. Therefore, following the pilot phase, this issue was discussed with the local collaborator, and it was agreed that for any subsequent interviews conducted in the hospital setting,

a room outside of the ward setting would be selected, if appropriate, to minimise the chance of any disruption.

6.2.3.3 Interview schedule

As discussed in chapter 5, unstructured interviews were selected as the method of data collection employed in the pilot study. This therefore determined the type and number of questions asked in the interview. The opening question in the first interview was 'What does cancer mean to you?' This question was well received by the participants; they appeared to understand what I was asking them and they could easily reply. In each case, this question evoked a number of replies which were then noted and used to set the participant-led agenda. The second interview started with the question 'Is there anything from our last interview that you would like to talk about?' Using this question, the aims of the second interview did appear to be met allowing more in-depth exploration of points that had been previously raised and the uncovering of 'new' issues which were not discussed in the first interview.

6.2.3.4 Interview technique

My interview technique was reviewed by my supervisory team once I had conducted the first two interviews. This entailed them reading

the transcripts and making a number of suggestions on how the interviews could be improved. Suggestions included:

- The use of more probing questions to encourage discussion and gain greater depth and understanding of the participants' experiences (Why? How? Can you tell me more about that? Tell me what you were thinking? How did you feel?)
- Reflecting, summarising and stating that I would like to go back and talk about issues raised in turn
- Using and feeling comfortable with silences
- Not being afraid to 'unpack the obvious'

These techniques were used in subsequent interviews in the pilot study and assisted in the in-depth exploration of pertinent issues related to the topic under investigation. By using such probes, participants engaged in conversation about the meaning of their experiences and how they made sense of what was happening to them, fitting within the realms of the selected methodology and the aim of the study.

6.2.3.5 *Confirming the perspectives of the patient*

When planning my study, I wanted my interpretations of what had been said in the interviews to be confirmed by the participants as I

felt that this would act as measures of rigour (Yardley 2000) in the study. Therefore, in the pilot phase I provided the participants with an overview of what had been said in the previous interviews. Whilst the two participants who were interviewed twice did agree with the summaries I offered to them regarding what they had said, one of the interviewees did comment that she felt embarrassed when being informed about what she had talked about previously and felt that she was 'moaning about their illness'.

Forbat and Henderson (2005) have reported similar accounts in their paper on the 'theoretical and practical reflections on sharing transcripts with participants. They report that 'one sees not only empowerment and ownership but also surprise and embarrassment' and they call for a 'more considered and reflexive approach to understanding the process of sharing transcripts with participants'. However, they also state that this process may also be 'extremely fruitful in achieving the desired research objectives, such as engaging participants to reflect further on their first interview and to check details or add to their initial conversation' (Forbat and Henderson 2005). On reflection, as the aim of the second interview was to explore in more detail some of the issues that were not probed in the first interview, to clarify details and to ask new questions based on close reading of the first interview transcript, I felt that this already

acted as a measure of the participants' agreements with what had been said previously. Providing participants with an additional summary of the previous interview was not thought to offer any additional benefit and had the potential to unduly embarrass or upset the participants. It was therefore decided that this process would be omitted in the main study.

6.2.3.6 *My reflexive thoughts on the interviews*

As stated in chapter 5, a reflexive journal was maintained by myself throughout the entire study. This included details on the daily schedule of the study, personal reflections, and a log for methodological decisions and accompanying rationales as advocated by Lincoln and Guba (1985). Throughout the pilot phase, the maintenance of a reflexive journal allowed me to explore my role in the research process. I found myself having to deal with the duality of the nurse researcher role; I identified myself with the work of Borbasi (2005), who reported that as a nurse she did not want to burden sick people with lots of questions but as a researcher wanted to extract as much information as possible (Borbasi 1996; Borbasi 1994). Furthermore, she noted that a number of patients wept during their conversations and she felt responsible for their anguish. Such feelings have also been reported by other nurse researchers conducting qualitative studies (Pellat 2003). With particular

reference to interviews in the pilot study, I did feel that these issues did prevent me from probing and further exploring pertinent issues raised. Through personal supervision and liaising with study supervisors/senior colleagues, these issues were discussed and a formal debriefing mechanism with senior colleagues was incorporated into the main study after each interview. I also ensured that the timings of the interviews were spaced out in the main study in order for me to have enough time to reflect on the previous interview.

Relative to the methods adopted in the study the reflexive journal allowed me to reflect on the unstructured approach which I had selected, the timing of the interviews and the questions that I had developed in order for me to address the aims of the study and the research questions posed. On reflection, no significant changes were made as I felt that the approach used facilitated the inductive bottom-up generation of data which I hoped to achieve. I felt that this approach provided the participants with the space and opportunity to talk about issues which were important to them in their lives, before talking in more depth about their experiences of symptom clusters. I felt that this approach allowed me to understand the context of the experiences of symptom clusters within the participants' lives, which, as a contextual constructionist (see

Chapter 4), I felt was crucial to me understanding the experience of symptom clusters in patients with advanced lung cancer.

6.2.4 Data analysis

All interviews were digitally recorded and transcribed verbatim by a member of the research support team. IPA was used to organise and manage the data in the pilot phase. The stages outlined in chapter 5 were used to analyse the data. Conducting this analysis in the pilot phase of the study served a number of purposes. It gave me the opportunity to engage in the practical application of IPA on my own data, and this was a good way for me to learn the core components of this analysis strategy. At the same time, it allowed me to critically review my interview technique and think about ways in which it could be improved. This process was pivotal in informing the iterative changes made in the main study.

In order to test the proposed data analysis framework, the interviews conducted with participant 2 were analysed. Given that the objective of the second interview was to clarify, explore in more detail and reflect on events in the first interview, it was felt that it was appropriate to analyse the two interviews together as a set.

Data analysis throughout the pilot study was assessed by one of the study supervisors. Feedback from the first attempt of analysis highlighted the lack of use of descriptive thematic analysis with the researcher moving on to a higher level of interpretation before this was completed. Such recommendations are reflected in the views of Smith and Eatough (2006) who state that the writing up of an IPA study should aim to 'to provide a close textual reading of the participants' account moving between description and different levels of interpretation of the data to a more highly, nuanced, interpretive and theoretical level' (Smith and Eatough, 2006:338).

Other suggestions made by the study supervisor included noting the participants' use of language (me, you, I), the use of similarities and differences, the use of particular words, the use of laughter, repetition, and changes in tone, such as moving from being hesitant to being articulate. Overall, the step-by-step framework advocated by Smith and Osborn (2003) was straightforward to use and therefore this method of data analysis was used throughout the main study.

6.2.5 Conclusions drawn from the conduct of the pilot study

In conclusion, the pilot phase of the study was particularly useful in identifying issues relevant to the conducting of the main study. In relation to the recruitment and consent of participants, it indicated the appropriateness of the procedures that were in place but highlighted the issue of an all female sample. Whilst the relevance of a male perspective in relation to the area under investigation was highlighted, in light of the selected methodology it was thought inappropriate to modify the sampling frame.

The timing of the interviews appeared to fit well with the study aims by facilitating an iterative process without unduly burdening the participants. The issue of attrition was raised as the first participant died shortly after the first interview, however, similar reports have been cited in the literature pertaining to research in people affected by cancer at the end of life and it was therefore decided that the scheduling of the interviews would remain unchanged. The setting of the interviews in the participants' homes or within the hospital environment did appear to facilitate the aims of the study by providing a relaxed and quiet atmosphere for the interview to take place, however, the limitations of conducting an interview within the hospital environment were noted. The pilot study raised some important issues related to the conduct of the interviews with

particular reference to the role of the researcher throughout this time. In particular, it highlighted the key role that the researcher played in this process, emphasising the importance of maintaining a close and reflexive record throughout the study.

Procedures to ensure rigour were assessed and re-evaluated, resulting in the decision not to feed back to participants an account of their previous interviews as the iterative approach adopted in the second interview appeared to address this issue. The analysis framework was tested and no significant problems noted in relation to its use in the subsequent main study. Overall, the pilot study was of extreme benefit in testing the proposed study design and procedures, allowing some minor modifications to be made prior to progressing onto the main study.

Chapter 7 Introduction to the results chapters

7.1 Summary of study results

The following two chapters present the results of this thesis. They detail the findings of two super-ordinate themes derived from this study: 'The lived experience of symptom clusters and the role of context and meaning', and 'Symptom clusters and loss of sense of self'.

The findings provide a rich portrayal of the lived experience of the symptom clusters in patients with advanced lung cancer. As stated in chapter 1, for the purpose of this thesis, a symptom cluster is defined as being the experience of three or more concurrent symptoms. This definition of symptom clusters is based on existing definitions of symptom clusters in patients with cancer which purport that 'concurrence' is a core characteristic of this phenomenon (Kim et al. 2005; Dodd et al. 2001b) and where the number of symptoms thought to constitute a symptom cluster is three or more (Dodd et al. 2001a; Dodd et al. 2001b). Furthermore, the characteristic of concurrence has been used as evidence of symptom clustering in previously published qualitative studies of symptom clusters in

patients with cancer (Lopez et al. 2011; Molassiotis et al. 2010; Molassiotis et al. 2008).

The findings correspond to the two research questions posed in this thesis by providing in-depth and detailed interpretation of the lived experience of symptom clusters in patients with advanced lung cancer and provide an insight into how people with advanced lung cancer understand and make sense of their experiences of this phenomenon. A brief overview of the findings is outlined below prior to their detailed presentation in Chapters 8 and 9 of this thesis. Table 12 details the super-ordinate themes, sub-themes and themes derived from this study.

Table 12: Super-ordinate themes, Sub-themes and themes derived from this study	
Super-ordinate theme	<ul style="list-style-type: none"> • Sub-themes ○ themes
The lived experience of symptom clusters and the role of context and meaning	<ul style="list-style-type: none"> • The experience of symptom clusters ○ Identifying 'salient' symptoms • Death ○ The meaning of lung cancer – death ○ Fear of death and the lived experience of symptom clusters ○ Fear of death and coping with symptom clusters • Stigma ○ Childhood recollections of stigma ○ Lung cancer – a self inflicted illness? ○ Stigma and the lived experience of symptom clusters
Symptom clusters and loss of sense of self	<ul style="list-style-type: none"> • The impact of symptom clusters on the self • Being a burden • Trying to maintain a coherent and valued self: ○ Comparing themselves to other people with cancer ○ Normality

Chapter 8 presents the first super-ordinate theme which is titled 'The lived experience of symptom clusters and the role of context and meaning'. The first sub-theme presented in this chapter, 'The experience of symptom clusters', illustrates how the participants in this study were experiencing symptom clusters, and how they linked

together several of the concurrent symptoms that they were experiencing, implying that they associated the occurrence of certain symptoms with others. The findings presented also illustrate the components of the symptom clusters experienced by the participants in this study, with four core symptoms (fatigue, pain, cough and breathlessness) identified as commonly occurring in the narrative symptom clusters reported.

This sub-theme also details how the narrative symptom clusters reported by the participants were most prevalent during times when they were receiving cancer related treatments such as radiotherapy and chemotherapy. During these periods, the participants commonly experienced several concurrent symptoms that were often transient in nature and diminished with time. However, of interest, and in contrast to these findings, was the observation that some symptom clusters did not diminish but appeared to remain constant over the patient trajectory. Furthermore, this sub-theme also details how some of the participants in this study used symptom clustering as a means of trying to deduce a cause for the symptoms that they were experiencing, with them often attributing the presence of one or two symptoms on the formation of another.

Further findings presented in this sub-theme also illustrate how the participants' narratives surrounding their experiences of symptom clusters often entailed them highlighting one 'salient' symptom from all the rest that they were experiencing, thus demonstrating that the participants did not appear to view all of their symptoms as having equal weighting, but did appear to give some symptoms greater credence over others. As will be evident in chapters 8 and 9 of this thesis, the significance of these specific symptoms to the individual from all the rest that they were experiencing, appeared to be strongly influenced by the context of a lung cancer diagnosis and the meanings that they ascribed to this symptom. In this study those meanings were commonly a fear of death, stigma and loss of sense of self.

This chapter then details the remaining two sub-themes informing the super-ordinate theme of 'The lived experience of symptom clusters and the role of context and meaning' which are entitled 'Death' and 'Stigma'. The findings presented within each of these sub-themes, demonstrate how the context of being diagnosed with a terminal illness such as lung cancer and its association with self-infliction, resulted in many of the participants ascribing negative meaning to their illness (which in this study was fear of death and stigma) and how this negative meaning in turn influenced their

experiences of symptom clusters and how they made sense of and understood such experiences.

The sub-theme 'Death' starts by describing in detail the wider context of the participants' experiences of being diagnosed with a life-limiting illness such as lung cancer, and how this manifests in an inherent fear of death which appeared to be far reaching and ever present. The section that follows detailing the theme 'Fear of death and the lived experience of symptom clusters' then describes how this context of being diagnosed with a life-threatening illness appeared to significantly influence the participants' experiences of symptom clusters, with many of them ascribing this negative meaning (fear of death) to their experience of this phenomenon.

Such findings, relative to the experience of symptom clusters, were most apparent at times when the participants experienced concurrent symptoms of high severity where their synergistic effect and the significant debilitation they caused appeared to signify to the participants that the threat of death was nearing.

This fear of death associated with the wider context of a lung cancer diagnosis also appeared to influence the participants' interpretation of symptom clusters in the way that they appeared to pick out salient symptoms from all the rest that they were experiencing and this appeared to be due to these symptoms in particular being symbolic of their mortality. Such findings therefore provide insight on how people with advanced lung cancer understand and make sense of their experience of symptom clusters by picking out salient symptoms from all the others that they are experiencing, based on the meanings that they ascribe to them.

The theme 'Fear of death and coping with symptom clusters' further illustrates the core role of context and meaning in the experience of symptom clusters and how the fear of death associated with a lung cancer diagnosis, not only directly influenced the participants' experiences of symptom clusters, but also affected the way that they coped with them. The participants' fear of death, coupled with a desire to live, resulted in them often tolerating multiple symptoms of high severity due to their cancer treatments in order to live another day. Such findings therefore highlight how the meanings that the participants ascribed to their experience of symptom clusters, in turn, influenced how they coped with them, often resulting in significant distress within the individual.

The third sub-theme supporting the super-ordinate theme of 'The lived experience of symptom clusters and the role of context and meaning' is 'Stigma'. This sub-theme is supported by three themes which are: 'Childhood recollections of stigma', 'Lung cancer – a self inflicted illness?' and 'Stigma and the lived experience of symptom clusters'.

The first two themes presented in this section, 'Childhood recollections of stigma' and 'Lung cancer – a self inflicted illness?' illustrate, in the first instance, how the context of being diagnosed with lung cancer and its association with self-infliction resulted in many of the participants associating an element of stigma to their disease. Such feelings of stigma were not only influenced by the participants' current experiences of lung cancer, but also by their past experiences of cancer as a child where the disease was often stigmatised and excluded by society.

The third theme, 'Stigma and the lived experience of symptom clusters', follows on from these two themes, and illustrates how these contextual factors described above significantly influenced the participants' experience of symptom clusters. As with the previous section detailing the theme of 'Fear of death and the lived experience

of symptom clusters', what was apparent and of significance to this thesis, was the way that despite experiencing symptom clusters, the participants would often focus many of their dialogues on individual symptoms. In this study, this focus on specific symptoms, within the experience of symptom clusters, was often due to the associated feelings of 'felt' stigma that the participants ascribed to a particular symptom. This symptom appeared to be selected from the other concurrent symptoms experienced, based on the participants' perceptions of its potential to attract the attention of others, particularly in public places, and therefore pose the risk of potential discrediting if strangers were to find out that their symptom was due to a lung cancer diagnosis.

The second super-ordinate theme informing this thesis is 'Symptom clusters and loss of sense of self'. This super-ordinate theme illustrates the impact of symptom clusters on the participants' lives, and how this, in turn, impacted on their sense of self in a number of different ways. The first sub-theme informing this super-ordinate theme, 'The impact of symptom clusters on the self', describes how the symptom clusters that the participants were experiencing resulted in them no longer being able to undertake many of the activities and roles that they had become accustomed to in the past and upon which they had built positive self-images. This in turn

imposed significant restrictions on their life which impacted on their sense of self, as they could no longer claim identities based on prior activities, interests or pursuits.

Of particular relevance to this thesis and the concept of symptom clusters in patients with cancer was the way that the participants' narratives surrounding this 'loss of sense of self' focused commonly only on one or two symptoms, despite them reporting to be experiencing several concurrent symptoms at this time. Symptoms such as fatigue and breathlessness appeared to be of particular importance to the participants and their sense of self, due to their link with impaired physical functioning, and therefore their importance in determining which activities/roles that the participants could or could not undertake. Such findings therefore highlight how, within the experience of symptom clusters, the participants did not appear to view all of the symptoms that they were experiencing in the same way, as the current evidence base would suggest, but appeared to give particular symptoms greater priority over others based on the perceived impact of these symptoms on their sense of self and their life.

The sub-theme of 'The impact of symptom clusters on the self' also highlights the central role of the body in the experience of symptom clusters, and how, at times, when the participants experienced symptom clusters of high severity, the body which they had become accustomed to became 'alien' to them, resulting in a transient loss of sense of self, causing considerable distress to them.

The sub-theme that follows, 'Being a burden', demonstrates the 'knock-on effect' of the experience of symptom clusters on the self. This sub-theme describes how the participants' sense of self was further fractured by the dependence that their multiple, concurrent symptoms created on others, resulting in the participants feeling they were a burden, which further resulted in increased suffering and emotional upset.

The third sub-theme informing this super-ordinate theme, 'Trying to maintain a coherent and valued self', further illustrates the far reaching effect of the experience of symptom clusters on the participants' lives. It describes how the participants, in light of the loss of sense of self experienced as a result of the symptom clusters that they were experiencing, employed strategies such as social comparison and accessing 'normality' to try and maintain a sense of

the person they were before their lung cancer diagnosis. Therefore, having presented a summary of the results of this study, the following section will detail the study population recruited to this study.

7.2 Study Population

A total of 10 participants took part in this study between May 2007 and February 2008. This sample size is the upper limit of the number of participants advocated for studies employing IPA (Smith et al. 2009b; Reid et al. 2005; Smith and Osborn 2004). The mean age of the participants recruited to the study was 63 years; most of the participants were female and all had advanced lung cancer.

Data on occupation, educational level, deprivation index and ethnicity of the participants were not formally collected in this study and therefore are not detailed in table 13 below. Participants were recruited from a district which is in one of the most deprived areas of Scotland, with high levels of unemployment and people living on a low income (<http://www.scotland.gov.uk/Topics/Statistics/SIMD>). In line with the selected methodology (IPA), all the participants were given pseudonyms.

Table 13: Characteristics of participants recruited						
Pseudonym	Gender (Male/Female)	Age (years)	Stage	Treatment	Additional Information	Concurrent symptoms experienced on recruitment to the study
Flora	Female	80	IV	Chemotherapy Radiotherapy	Flora has several children. Matriarch of the family. Independence of prime concern to her – does not want the family to take over. A few family members living with her but she continues to cook for them and look after grandchildren.	Lack of appetite, hair loss, fatigue, dizziness, rash, pain
Veronica	Female	58	IV	Chemotherapy Radiotherapy	Lives with husband who now undertakes all household chores. Does very little now except go to and from hospital. Very despondent and angry about lung cancer diagnosis. Scared to leave loved ones behind, feels like her life has been taken away from her.	Nausea, vomiting, dry mouth, swollen legs, lack of appetite, fatigue, breathlessness

Emily	Female	64	IV	Chemotherapy	Lives with husband who is the main carer and now undertakes most household chores. Cannot go anywhere on her own anymore – always needs to be supervised. This makes her angry. Angry at illness – prevents her from accessing normality. Views herself as being different from other people who do not have cancer - 'insider looking at the outside world'	Cough, fatigue, nausea, vomiting, feeling low, dizziness, pain, hoarse voice, breathlessness
Dan	Male	63	IV	Chemotherapy	Lives with wife, son and daughter. Views himself as being the main provider for the family. Has continued to work since being diagnosed with lung cancer – this is a central coping mechanism for him. Scared of what the future will hold.	Cough, breathlessness, lack of appetite, weight loss, fatigue, gastritis
Paul	Male	63	IIIb	Chemotherapy	Lives alone. Divorced from wife, only recently revived relationship with children. Has had lots of turmoil in life – regrets the past, now has a renewed sense of the value and simple things in life.	Breathlessness, lack of appetite, weight loss, nausea, vomiting, pain, burning on the sole of his feet

Thomas	Male	58	IIIb	Chemotherapy	Lives with family. Has now stopped work. One of his main frustrations is that he cannot help people anymore. Viewed by friends and family as the 'handyman' – he can no longer maintain this role and this causes considerable distress to him	Cough, lack of appetite, fatigue, nocturia, breathlessness
Jessie	Female	73	IV	Chemotherapy	Lives with husband who now does all of the household chores. Has two sons, one has a chronic illness which causes her much concern. Feels guilty that she cannot fulfil role of 'wife' and 'mother' – this makes her upset. Previously had a very active social life – much of this has now stopped due to her condition.	Breathlessness, lack of appetite, hair loss, fatigue, nocturia, headache, pain, constipation, 'feels cold all of the time', insomnia, swollen legs
Suzie	Female	68	IIIb	Surgery Chemotherapy	Lives with husband. Still shocked that she developed lung cancer as she was not a smoker and led a healthy lifestyle. Appears to be embarrassed that she has this disease. Appears to try and conceal it from others.	Breathlessness, weight loss, hair loss, vomiting, fatigue, pain, mouth ulcers

Richard	Male	58	IIIb	Surgery Chemotherapy Radiotherapy	Lives with wife. Children now married but visit regularly. Feels that he is the main provider of the family, wants to protect them from his illness. Lives in a constant fear of death – now appreciates the simple things in life. His father died of lung cancer and this appears to have been a significant factor in his experience of his illness.	Weight loss, fatigue, nausea, vomiting, dysphagia, pain, hair loss
Ruby	Female	47	IV	Chemotherapy	Lives with husband who now undertakes most of the household chores. Daughter lives in England and has recently had a baby daughter. Visits her mother on a regular basis with the baby. Ruby is distraught by her illness, and fears what will happen to her family when she is no longer there.	Cough, hair loss, nausea, dizziness

7.3 Details of interviews

All interviews lasted between 45 and 70 minutes. Most of the participants opted to be interviewed at home (n=6), however, some preferred a quiet room in the hospital, which often coincided with days/times that they had appointments at the hospital. Three patients died during the period between the first and second interview (Paul, Veronica and Ruby) and therefore only participated in one interview.

Having provided a summary of the results, provided details of the study sample recruited to the study and details regarding the interviews that were conducted in this chapter, the following chapter of this thesis will present the results of the first super-ordinate theme of 'The lived experience of symptom clusters and the role of context and meaning'.

Chapter 8 The lived experience of symptom clusters and the role of context and meaning

This is the first of the two results chapters of this thesis, and details the super-ordinate theme 'The lived experience of symptom clusters and the role of context and meaning'.

This chapter illustrates in the first instance that the participants in this study talked about their experiences of symptom clusters, associating at times the occurrence of certain symptoms with others. The findings also illustrate the constituents and patterning of symptom clusters reported by the participants, highlighting common cluster symptoms that were experienced (fatigue, cough, pain and breathlessness), symptoms that tended to co-occur together and the timing, duration and nature of the symptom clusters reported. This chapter also provides insight into how people with advanced lung cancer understand and make sense of the symptom clusters that they are experiencing, using concurrence as a means of trying to find a cause for the symptoms that they were experiencing.

The findings described in this chapter also highlight that within the experience of symptom clusters, the participants in this study did not

appear to view all of the symptoms that they experienced as being of equal importance, but instead singled out specific symptoms which were of particular salience to them. As described in this chapter and the one that follows, this 'singling out' of symptoms within the context of symptom clusters appeared to be related to the meanings that the participants associated with these symptoms, which, in this study, were commonly a fear of death, stigma and loss of sense of self.

8.1 The experience of symptom clusters

As stated above, the participants in this study did talk about their experiences of symptom clusters. Many of the participants' narratives surrounding their symptom experiences depicted symptoms as co-occurring in groups, providing evidence of symptom clustering. Such findings are exemplified by the following quote by Richard, who experienced multiple symptoms such as pain, fatigue, nausea and vomiting, and hair loss during his radiotherapy treatment. His dialogue suggests that this experience was one of his worst to date, due to the profound debilitation that his symptoms caused. Within his quote, there is also a sense that Richard perceived the multiple symptoms that he experienced as having a cumulative effect, all contributing to the high symptom burden that he experienced during this time:

Richard: ...for about two weeks – awful ... absolutely awful, the worst feeling ever ... you know, you were just ... your arms were sore ... your legs were just ... just totally knackered, that's the best way I can describe it ... and you, you had the sick feeling, you know ... and a couple oh times I was physically sick eh ... the hair was getting thin, no that I've got a lot of hair anyway, but ... it was getting thinner, you just did'nae feel right at all ... I don't know if I've described it properly, but that was how I felt – awful; absolutely... (Richard, interview 1, page 43).

Within the participants' dialogues surrounding their experiences of symptom clusters, what was also apparent was the way that they did appear to associate the occurrence of certain symptoms closely with others. This perceived association between symptoms is illustrated in the following brief quote by Jessie. In this quote, we can see how Jessie talks about the multiple symptoms that she is experiencing at this time, such as fatigue, insomnia, nocturia and swollen legs. In her description, it is apparent that she links her fatigue to her insomnia, which is in turn attributed to the Frusemide she takes to treat her oedematous legs. The way that she describes such experiences as being a 'vicious circle', suggests that this pattern of events is never ending, and constantly repeats itself.

Jessie: I could sleep, I mean even if I get up, have my breakfast, get washed and dressed and sit down I fall asleep again, fall asleep in the car, I think I've got sleepy sickness ... [laughter] ... but having said that you see I can be up quite a few times during the night, so I'm no really getting a proper

sleep through the night, you know wi' the, eh .. up to go to the toilet, through the night. You take your Frusemide, you don't take the Frusemide your legs aw swell up, it's a vicious circle aint it, but eh ...' (Jessie, interview 1, pages 45-46).

Within the participants' narratives surrounding their experiences of symptom clusters, four core symptoms (fatigue, pain, cough and breathlessness) were commonly cited as being associated with the occurrence of several other co-occurring symptoms. Only one symptom cluster depicted in the participants' narratives did not consist of one of these core symptoms.

Fatigue was the most common symptom cited by the participants as co-occurring with other symptoms, followed by pain, cough and breathlessness, respectively. Other symptoms that were identified as co-occurring with these core cluster symptoms included insomnia, headache, nausea, vomiting, nocturia, feeling low/depression, myalgia, hair thinning, diarrhoea, and burning on the soles of the feet (see table 14 below).

Table 14: Symptom clusters identified from participants' narratives during interviews
Symptom clusters associated with fatigue
Fatigue, feeling low, pain
Fatigue, cough and pain
Fatigue, cough, breathlessness, depression
Fatigue, nocturia, constipation, headache
Fatigue, nausea and lack of appetite
Fatigue, weakness, lack of appetite
Fatigue, insomnia, cough
Fatigue, feeling low, pain
Fatigue, pain, asthenia, nausea, hair thinning
Fatigue, breathlessness, anxiety, pain
Symptom clusters associated with cough
Cough, fatigue, pain
Cough, fatigue, breathlessness, depression
Cough, fatigue, insomnia
Cough, breathlessness, pain
Cough, gastritis, breathlessness
Cough, nausea, vomiting
Cough, breathlessness, nausea, vomiting
Symptom clusters associated with pain
Pain, fatigue, feeling low

Pain, fatigue, cough
Pain, cough, breathlessness
Pain, breathlessness, anxiety
Pain, nausea, breathlessness
Pain, fatigue, asthenia, nausea, hair thinning
Pain, insomnia, burning of the soles of the feet
Pain, breathlessness, anxiety, fatigue
Symptom clusters associated with breathlessness
Breathlessness, fatigue, cough, depression
Breathlessness, cough, pain
Breathlessness, cough, gastritis
Breathlessness, cough, nausea, vomiting
Breathlessness, pain, anxiety
Breathlessness, nausea, pain
Breathlessness, anxiety, pain, fatigue
Clusters without core symptoms (fatigue, cough, pain, breathlessness)
Shivering, sweating, feeling cold

Within the participants' narratives, symptoms that frequently co-occurred with the symptom of fatigue were feeling low/depressed and pain. The following excerpt from Emily highlights such associations when she talks about the symptoms that she experienced due to her

chemotherapy treatment. In her account, she describes the knock-on effect of her fatigue on the occurrence of other symptoms such as pain and feeling low:

Emily: ...but eh, I still feel quite tired right enough, no sleepy tired just tired, like I can't be bothered, I feel as if I start to do things and then ... my body gets sore, my legs get sore, and maybe that's an excuse for me to go and sit down, I don't know but eh, that can get you a wee bit down at times as well.. (Emily, interview 1, page 25).

For other prevalent cluster symptoms such as cough, this symptom was observed to commonly co-occur with breathlessness. Such findings are exemplified in the brief quote by Dan, who talks about how his cough leads to the occurrence of his breathlessness:

Dan: [coughs] well it's, I would say in the last couple oh months eh, it's just, it started oaf wi' a tickly cough and when you've goat the cough you get breathless, eh (Dan, interview 1, page 40).

Symptoms that were noted to commonly co-occur with pain within the participants' narratives were fatigue and breathlessness. This clustering of symptoms is best illustrated in the following quote by Jessie who talks about how she feels when she is breathless. Her

narrative describes the symptoms which co-occur with her breathlessness, such as pain and fatigue. She appears to be shocked at the significant impact that her symptoms have upon her, particularly their rapidity. Although she uses humour, there is an underlying sense that she is embarrassed at the way that she falls asleep during such episodes, however, her dialogue also suggests that she has little control of her actions at this time:

Roma: And how do you feel when your breathless, can you tell me a wee bit more about how you're feeling?

Jessie: Aye, panicky, panicky and, and sore across my chest and you're sitting [makes panting sounds] ... I mean I have actually, haven't I, I cannae get away wi' it myself, I have to come up the stairs, plank masel doon here [makes a puffing sound] still got my jacket on and fell asleep. I mean I used to [.....] sitting there wi' yer jacket on and I'd just go ...

Carer: But eh...it's sitting down, just ...

Jessie: ... and that's me away to sleep [laughs] oh I could sleep at the drop oh a hat - anytime (Jessie, interview 1, pages 44-45).

For many of the participants, symptom clustering appeared to be most prevalent at times when they were receiving cancer related treatments such as chemotherapy and radiotherapy. At such times the participants would describe the multiple symptoms that they experienced and their cumulative impact upon them. However, what

was also noticeable was the way that these clusters of symptoms did appear to diminish over time. The following quote, also from Jessie, best demonstrates this point, when she talks about the multiple symptoms that she experiences for two or three days following her chemotherapy treatment:

Jessie: You're just so, so tired, really I've been just, so tired that I, I could sleep at the drop oh a hat. But I mean I'm prepared for that, it tells you in the literature eh, wi' your different chemos that you will be tired and you've got tae gie yerself time for rest, I just did'nae realise how tired ... [laughs] ... I'm definitely like Rip Van Winkle, I mean as I say I can get up, get washed, dressed, get my breakfast, sit doon here and go [makes snoring sound] ... faw 'sleep. Now you should'nae really be tired after you've been in bed aw night but as I say, it's broken sleep through the night, you know, you're getting up to, to go the toilet quite a few times and there's a, a stage isn't there when the, wi' the chemo, but I don't know how to explain it ... it's like ... there's a stage where, you know, you're no too bad and then you get, suddenly you're up and doon and up and doon and up and doon at that toilet ...

Carer: Oh, aye, aye

Jessie: ... I don't know why it goes like that and then that disappears and you have a ... a bout oh constipation so you take they thingies, whatever they're called ... or ...

Carer: Senna

Jessie: Senna, aye, I take a Senna and I'm ok and next day, eh, I don't take diarrhoea wi' that right enough, but eh, and I always seem to get a headache at some point during the ..

Carer: It's when, it's when yae get the build-up of fluid, after the chemo she seems to gets a wee build oh fluid for a couple oh days and then, one ... it usually happens one, it's probably because she's lying down, she eh, the fluid starts to

come off again and she [...] down all night and that's when you get up in the morning you've usually got a sore head, but I think it's to do wi' the amount of fluid going, coming off...mm mmm, bit oh a, bit oh a headache ... but it goes away, you know, the headache goes away, mmm mmm

Carer: I think that's tied up wi' that

Jessie: Aye, it could be [...]

Carer: But it, it seems to happen every time she takes this chemo, you know, two or three days after it she gets this wee bout, but we know it's only going to last a day and then ...

Jessie: Aye and it goes away again, you know ..(Jessie, interview 1, pages 51-53).

From the quote above, the ephemeral nature of the cluster of symptoms that Jessie experiences is apparent. Her dialogue details the patterns of her multiple symptoms at this time with some co-occurring and some diminishing as a new symptom arises. There is a sense that this patterning of symptoms repeats itself, as both Jessie and her husband appear to be familiar with the sequence of the occurrence of these symptoms and know when they will diminish.

However, on further exploration of the data, what was also of note was that for some of the participants, certain clusters of symptoms did not diminish, but were ever present. For example, for Emily, the cluster of cough, pain and fatigue did not diminish, but had been present since the pre-diagnosis stages of her illness. As will be

illustrated in the section and chapters that follow, Emily often highlighted her cough as being the most problematic symptom of all, and the chronic association of her cough with pain and fatigue may have attributed to her perceiving this symptom in such a negative manner.

For some of the participants, their linking up of co-occurring symptoms appeared to act as a way of them trying to make sense of the impact of the multiple symptoms upon themselves. The following quote, also from Emily, best exemplifies this point. In her previous interview she talked about how she associated her pain with fatigue, and is asked by the researcher in the second interview to elaborate on this statement. From the dialogue below, it appears that Emily tries to understand and make sense of the fatigue that she is experiencing by partly attributing this to her cough and insomnia. It may be inferred that by sourcing the cause of her fatigue, Emily feels more in control of her symptom and can therefore deal with the consequences of it within her life:

Roma: OK. Em, moving ... we talked a wee bit about your pain as well last time em, and you were talking about your pain and it says, you know, it drains your energy away, can you tell me a wee bit more about that, why you described it like that, in that way?

Emily: Well, I just assume that's part oh why I feel at times really, no energy, you know and you just think well, between not sleeping very good and the cough and whatever, just an accumulation of things eh, that's probably what I mean it's, kind of draining, just a lot of different wee things that, all goes into one big thing and, you just don't feel very good when it's happening.. (Emily, interview 2, page 49).

In addition to the characteristics of the experience of symptom clusters previously detailed, and, as briefly discussed above, what was also apparent in the participants' dialogues surrounding their experiences of symptom clusters, was the way that they would often highlight one symptom above the rest that they were experiencing.

This point is exemplified in the following quote by Dan:

Dan: I've lost a wee bit oh weight in the last month, I'll be perfectly honest wi' yae, I have lost, maybe about 6 pund, the last month, but that's through the breathing and God knows what, like, you know, cause your werenae feeling like eating. ... Well, I wisnae eating, that's why I ... that's the only reason I've lost weight, because I wisnae eating, you know, eh, loss oh appetite if you like through – possibility chemo. ... I was going doon, the breathing was getting to me and I was gradually sliding the wrong way, I'm usually sliding – "uphill" but wi' the breathing getting tae me I was sliding doon hill, but I was feart I was going to slide too far doonhill, you know what I mean ... Well eh, [name of nurse] and ... and aw that says it was your attitude, your approach that's kept you up you know eh, and with this breathing getting to me and so...[makes gasping sound] it does get you down (Dan, interview 2, pages 12-13).

As detailed in greater depth in this chapter and the one that follows, often this individual symptom was selected based on its symbolic connotations, which, in this study, were commonly a fear of death, 'felt stigma' and loss of sense of self. These findings are discussed in the first instance in the following section which details the theme of 'Identifying 'salient' symptoms', and then in greater depth in sections 8.2, 8.3 and in chapter 9 that follow.

8.1.1 Identifying 'salient' symptoms

As indicated above, what was noticeable in the participants' narratives surrounding their experiences of symptom clusters was the way that they tended to highlight one specific symptom from all the rest that they were experiencing, and, as illustrated in the results chapters that follow, this appeared to be primarily attributed to meanings that the participants associated with this symptom.

From all of the participants, the narratives from Emily best exemplify this point. Emily talked about her experiences of symptom clusters on several occasions throughout both of her interviews, often describing the significant debilitation and distress that they caused. However, within many of her dialogues surrounding her experiences of symptom clusters, she commonly highlighted her cough as being

the most problematic symptom of them all. Of significance, and as discussed in greater depth in section 8.3 of this chapter, is the way that Emily associated her cough with feelings of 'felt stigma', and this in turn may explain why she perceived her cough in such a negative way.

In the extract that follows we see how Emily talks about her experiences of multiple symptoms such as cough, breathlessness, and pain. However, in her dialogue it is also apparent that she views her cough as having a negative influence over all the other symptoms that she experiences and this is implied by the way she states that the '*coughing generally makes things worse*'.

Emily: Eh, I've no really, I mean, the coughing generally makes things worse and that's generally at night eh, or that, but if I'm getting short of breath sometimes I get a bit of pain... (Emily, interview 2, pages 58-59).

This highlighting of her cough from all of the other symptoms that she experienced occurred on a number of other occasions throughout Emily's interviews. In the following excerpt we also see how she highlights her cough as being the main contributor to the pain that she experiences.

Emily: Well eh ... the coughing, as I said, sometimes you've got no pain but, till you start coughing and eh, it's just that it catches you in between your shoulders eh, and I think because you're coughing so hard you feel as if it's, the pain's going right down to the bottom of your back, round your waist, but eh, when the coughing subsides, that seems to get a bit better as well, it disnae go away, these things never do but, the coughing definitely aggravates it I think, and that's when you feel the pain more.. (Emily, interview 1, page 51).

This highlighting of a particular symptom was also apparent in Jessie's narratives surrounding her experiences of multiple symptoms. In the previous extracts we see how Jessie experienced several concurrent symptoms such as breathlessness, lack of appetite, hair loss, fatigue, nocturia, headache, pain, constipation and insomnia. However, in the short quote that follows, we can see how Jessie highlights her breathlessness as being the most frightening symptom of all. Such findings can be further explained with reference to section 8.2 that follows, detailing the theme of 'Fear of death and the lived experience of symptom clusters', which illustrates how the participants' experiences of symptom clusters were frequently situated within a fear of death.

Jessie: I think that's the most frightening of the lot is the breathing, you know when you ... you cannae breathe properly you, you kinda panic... (Jessie, interview 1, page 43).

This highlighting of individual symptoms within the experience of symptom clusters is further exemplified in the following brief quote from Dan. Despite experiencing several concurrent symptoms, such as cough, breathlessness, lack of appetite, weight loss, fatigue and gastritis (see table 13), we see how sentinel the symptom of breathlessness is to him. His use of the word 'perfect' to describe a state where he is not breathless, highlights the central significance of this symptom to him and suggests that he gives this symptom superiority above all the rest that he is experiencing at this time:

Dan: See, if I could breathe, I'd be perfect within myself – perfect (Dan, interview 2, page 52).

The first sub-theme presented in this chapter, 'The experience of symptom clusters', has illustrated how the participants in this study did talk about their experiences of symptom clusters, and appeared to associate the occurrence of certain symptoms with others. It also highlights that within the experience of symptom clusters in patients with advanced lung cancer, four core symptoms exist (fatigue, cough, pain and breathlessness) which commonly feature in the narrative symptom clusters depicted by the participants.

The results presented in this sub-theme also demonstrate that occurrence of symptom clusters in patients with advanced lung cancer is most prevalent during periods of treatment. The participants' descriptions of symptom clusters at such times often depicted the transient nature of symptoms, with many occurring and then diminishing with time. However, in contrast, some of the clusters described by the participants did not appear to follow this trend, but appeared to remain constant throughout the patient trajectory.

The findings illustrated in this sub-theme also provide insight into how the participants in this study made sense of the symptom clusters that they were experiencing, often using the co-occurrence of symptoms as a means of sourcing the cause of another symptom.

However, of particular significance is the way that the participants, within the experience of symptom clusters, commonly chose to emphasise and highlight individual symptoms that they were experiencing. This is characterised in the following quotes by Richard when he talks about his experiences of radiotherapy:

Richard: ... for about two weeks – awful ... absolutely awful, the worst feeling ever ... you know you were just ... your arms were sore ... your legs were just ... just totally knackered, that's the best way I can describe it ... and you, you had the sick feeling you know ... and a couple oh times I was physically sick eh ... the hair was getting thin, no that I've got a lot of hair anyway but ... it was getting thinner, you just didnae feel right at all ... I don't know if I've described it properly, but that was how I felt – awful; absolutely awful, (Richard, interview 2, page 12).

Richard:... but I lost a lot of weight I lost nearly 2 stone during that period, I couldn't swallow e-r-r but they told me this was [coughs] part of the treatment where they were aiming the radiotherapy it will affect me ... You know, the ... what have you, so I was ... I couldnae swallow so I wasn't eating I was drinking a lot of fluid, e-r-r, and I felt bad at losing the weight, I started to worry about that, e-r-r and again my own GP, he was brilliant, don't worry about it, it's normal, it'll come back on to you, your weight will come back and it has, you know everybody has told me this and it's came that way (Richard, interview 1, page 29).

As will be further illustrated in the sections and chapter that follow, the prominence of these individual symptoms within the experience of symptom clusters was commonly mediated by the meanings that individuals ascribed to these symptoms. In this study, these meanings were commonly a fear of death, stigma, and loss of sense of self. This is discussed in greater depth in the sections that follow.

8.2 Death

This section of this thesis details the second sub-theme 'Death', which informs the super-ordinate theme of 'The lived experience of

symptom clusters and the role of context and meaning' derived from this thesis. This sub-theme and the one that follows ('Stigma') illustrates how the context of being diagnosed with a life-limiting illness such as lung cancer and its association with self infliction, resulted in many of the participants ascribing negative meaning to their illness. This chapter also highlights how this context and the negative meaning the participants associated with their illness in turn influenced their experiences of symptom clusters, with them often attributing these negative meanings to their experiences of this phenomenon. Such findings therefore highlight the core role that context and meaning play in the experience of symptom clusters in patients with advanced lung cancer.

The section that follows provides data in the first instance to illustrate the context of a lung cancer diagnosis and how the participants in this study associated their illness with an overwhelming fear of death. The sections that follow then demonstrate how this context of fear of death significantly influenced the participants' experiences of symptom clusters by the way they used these negative meanings to understand and make sense of their experiences of this phenomenon.

8.2.1 The meaning of lung cancer - death

When asked at the start of the first interview 'What does cancer mean to you?', many of the participants replied to this question by talking about their fear of death. This is not surprising in light of the terminal nature of their disease and the limited survival rate (Sola et al. 2004; International Agency for Research on Cancer 2000). This fear of death provided a context for many of the participants' experiences of symptom clusters (see section 8.2.2).

Perhaps the most extreme example of this fear of death associated with the context of lung cancer diagnosis was provided by Ruby, a 58 year old woman who had recently been diagnosed with lung cancer and was told that she only had months to live. Here she talked about her '*fear of the unknown*':

Roma: ... when I said to you, "What does cancer mean to you?" and you said "devastation", can you explain a wee bit more what you mean by that?

Ruby: Your life's in turmoil. Em ... I'm frightened oh the unknown ... eh ... the treatments ... the treatment makes you feel terrible, em ... your immune system's always down, well, not always down, but you've tae watch. You cannae go oot, you know, mixing ... even in shops, things like that, you know ... you've to watch what you're doing, eating ... well I eat well anyway ... it's just frightened oh the unknown, the unknown.

Roma: If you can, can you tell me a wee bit more about that...?

Ruby: The unknown?

Roma: Being frightened of the unknown...

Ruby: Well, that Dr [name] ... he told me I'd a year to live and it's my daughter and my ... my grandchildren and my husband, you know ... it's, you're frightened oh leaving them, you're no wanting tae leave them, you know ... so ... [sounds emotional] (Ruby, interview 1, page 2).

Ruby's words cut straight to the core, like most of the participants she explains several key aspects of the experiences of living with cancer: the impact of treatment and the limitations that brings. However, the extract brings with it a sense of fear and this is implied in the difficulty she has when talking about the likelihood of her death. The way that she does not openly use the word 'death' and talks about the 'unknown' and uses euphemisms when talking of 'leaving' her grandchildren and husband suggests some sense of avoidance; she knows she is going to die but appears to find talking about it too distressing.

The innate fear of death expressed by Ruby was also reflected in the accounts of many of the other participants. What was apparent was that this fear of death was not something that came and went but

was omnipresent. In their narratives, their fear of death was perceptible throughout many of their interviews.

The following quote from Richard highlights this when he talks about his fear of death, which he describes as being the 'fear factor'. Of all the participants, Richard's fear of death appeared to be most prominent and this may have been due to his past experiences of his father dying of lung cancer. The use of the term 'fear factor' to label his fear of death suggests that it is something that is highly important to him and prominent in his life. It may be also be inferred that by giving his fear a label, Richard can contain it and make it easier to control:

Richard: ... but the fear is always there, you are, you're frightened, aye ... that's the best way to describe it, fear, the fear factor, you know ... you deal wi' that as well ... you try and put it in the back oh your mind, but it always surfaces ... fear always surfaces ... (Richard, interview 2, page 7).

8.2.2 Fear of death and the experience of symptom clusters

This fear of death, stemming from the wider context of being diagnosed with a life-limiting illness such as lung cancer, in turn,

significantly influenced the participants' experiences of symptom clusters.

For some of the participants, this context of a fear of death, manifests itself at times when the participants experienced concurrent symptoms of high severity due to the treatments that they were receiving. There was a sense that at such times, in light of their failing bodies, they felt that the threat of death was nearing, as they were afraid that they would not recover from such episodes and would die. The following two excerpts from Flora exemplify this fear of death when she talks about how she felt '*terrible*' after her radiotherapy treatment. Such experiences were profoundly distressing for Flora as they threatened her independence, something which she greatly valued and strived to maintain in her life.

In the first quote presented below, Flora talks about the significant debilitation that she encountered due to the concurrent symptoms that she experienced following her radiotherapy treatment. The incapacitation that she experiences due to her symptoms is apparent, with her only managing to perform the most basic activities of daily living:

Roma: And when you were feeling weak after the radiotherapy can you explain a wee bit more about that?

Flora: Weak, I could hardly do anything, it took me all my time, it gave you a very tired feeling, it took you all your time to get out of bed and put your clothes on, sometimes I just put my dressing gown on, and come down, I still had my nightie on, you know, that's how weak it felt, you know. But after a week I started to get better again, mmm mmm. But I really felt ill for a week, I did ...

Roma: ...And when you were feeling tired and weak ...

Flora : ...Tired, tired, as if I'd been ill, you know, say you had a bad illness, say like a chest infection or anything like that and you feel weak, I had one not so long ago didn't I, I had a chest infection and pleurisy, mmm mmm...

Roma: Can you explain a wee bit more about that, that feeling that ...?

Flora : Oh, the tired feeling after ...

Roma: Uh huh ...

Flora : Well, I was just dragging my feet behind me, I was ... that's when I let [daughter] make my dinner and that, you know, make my food and I was kinda off my food as well, mmm mmm, ... (Flora, interview 1, page 24).

Such experiences are further elaborated in the quote that follows, when Flora talks about her thoughts during this time:

Roma: And, and what were you thinking at the time, do you know, when you were, that week when you were feeling like that [week after radiotherapy]?

Flora: All I could think was "My gosh, I hope I get better, uh huh, this is a terrible feeling, uh huh". But I think someone told me, they must have in the hospital, that you don't feel

very well after radiotherapy, I had heard someone saying it and it was true, so I'll see when I, if I get this shoulder done in radiotherapy, I'll see if it was the same, you know, once I get this done, uh huh...

Roma: And when you say it was terrible, you might think these are silly questions, but it's to try and understand why you, you describe feeling that way, ... did you feel it was terrible the way you were feeling?

Flora: Well, why did I feel it was like that? Well, I'd never ever felt like that before, you know, I'd never felt like that before because I was always fairly healthy and got around, but it was horrible, mmm mmm. But I used to say to myself "I must get better, I will get better", and I did get better ...

Roma: Could, if, you know, if you want, can you tell me a wee bit more about that, about why you were thinking that at the time - "I must get better, I will" ... ?

Flora: Well, I had lots of things I wanted to do, you know ... yes, that's how I felt, there was lots of things I wanted to do, mmm mmm. I can't go just now, there's tons of things I want to do, mmm mmm ... [slight pause] ... (Flora, interview 1, pages 25-26).

In the second quote presented above, it is evident that Flora associates the severity of the concurrent symptoms that she is experiencing as being symbolic to her that the threat of death is near. She appears to be scared as she has never experienced this level of symptomatology before and therefore does not know what to expect. This uncertainty appears to 'fuel' the fear that she is experiencing. Her fear of death also appears to be magnified by her strong will to live and, for Flora, this may in part stem from the central role that she plays within her large family and their reliance

on her. She appears to try and cope with this threat of death by convincing herself that the high severity of her symptoms that she is experiencing is just to be expected as she has been told this in the past. She also appears to believe in the healing power of the mind, and uses this strategy to try and help herself recover from this episode in her illness.

This context of being diagnosed with a life-limiting illness such as lung cancer and the fear of death which ensued also influenced the participants' experiences of symptom clusters in another way. Despite all of the participants reporting to be experiencing several concurrent symptoms, of particular relevance to this thesis was the way that they dedicated much time and detail in talking about certain symptoms such as breathlessness, lack of appetite and weight loss. The significance of these specific symptoms to the participants, from all the rest that they were experiencing, appeared to stem from the way that they associated these symptoms with death. Such findings may be partly explained by the way that all of these symptoms (breathlessness, lack of appetite and weight loss) are reflective of the basic physiological requirements to maintain life.

This is best illustrated in the following quote by Dan. Despite reporting to be experiencing several concurrent symptoms at this time, here we see how he dedicates much time and detail when talking about his breathlessness. This focus on his breathlessness and the detail that he affords in describing it was not only apparent on this occasion but on numerous occasions throughout both of his interviews. The inherent fear of death which pervades his thoughts when he is breathless is evident. It appears that the longer his breathlessness lasts and the more severe it becomes, the more it turns into a 'real' experience to him. The use of this term by Dan suggests that when his breathlessness gets to the point of being 'real', the threat of death is no longer a possible or potential occurrence, but becomes a fact.

Roma: What were you thinking when you were feeling this breathlessness?

Dan: Oh Christ, you were thinking, "Is it your last minute?" Naw, no really like, you know, but, you're saying to yourself, "Christ I hope this disnae last too bloody long or if this gets worse they'll need tae dae something real," you know? Oh aye it's, it's just, that's the kind of stage you're at like, you know, what do we do next like, you know ... but what dae you dae next if you cannae get a ... if you cannae get a breath, Christ you might as well no be here ... you'll no be here, cause it's the breathing that keeps you going! (Dan, interview 2, page 14).

Such feelings may in part stem from Dan being told by the health professionals caring for him that his breathlessness may be a 'sign of the future' and that there may come a point when they can no longer treat his breathlessness. The thought of his breathlessness progressing to a level where there is no intervention appears to scare Dan. Although he denies it, there is a sense that such an existence would be so intolerable to him that he would contemplate ending his own life. Such thoughts of suicidal ideation were apparent on another two occasions during Dan's interviews when he talked about his breathlessness. Common to all was the feeling of hopelessness evoked in Dan when contemplating there being a time in the future when his breathlessness could no longer be treated and the consequences of this in his life:

Roma: OK. So, you know, we, we were talking about breathlessness before as well and you said it could be a sign of the future, when you were talking about your breathlessness ...

Dan: Well that's what I was getting to last week ... it was a sign oh the future, because they were telling me that eh, and there might no be nothing you can dae about it, well, I says, I wouldnae like to go a bit breathless like that. What I would dae, I don't think I would dae away wi' masel ... don't ... I'm no that bloody stupid ... (Dan, interview 2, page 16).

The fear of death derived from the context of a lung cancer diagnosis, not only permeated the participants' experiences of

breathlessness, but also other symptoms, such as lack of appetite and weight loss. As with the above, in relation to the experience of breathlessness, despite experiencing multiple, concurrent symptoms at this time, the participants appeared to focus much of their dialogue on these individual symptoms and this appeared to be due to the symbolic connotations of these symptoms with a fear of death. This focus on individual symptoms within the experience of symptom clusters implies that patients with lung cancer experiencing this phenomenon do not view all the symptoms that they are experiencing as being of equal priority, but tend to stratify them based on the meanings that they ascribe to them. This is exemplified in the following quotes by Paul when he talks about his chemotherapy treatment:

Paul: ... this time it's like a stronger dose and I was feeling a wee bit nausea and, I wisnae feeling too good about myself, right ... and eh, aye, I was just, I was getting the pains again ... I've no been eating ... (Paul, interview 1, page 12).

He then goes on to talk of his fear of being discharged home following his chemotherapy treatment, highlighting that his fear of going home stems from his inability to eat:

Paul: ... and again, it's going tae ma heed, he's wanting tae throw me oot and oh, that just get some of the nervous system going again, you know, that disnae help yae. They start tae calm yae doon and get food intae you, and he's upsetting yae and, a-a-w God, I begin tae sae tae masel, do they no read your case notes afore they come up, cause this is a doctor I've no seen, I've seen I don't know how many doctors have been up at me, but anyway, [name of nurse]'s like that, naw that'll no happen like that, don't you worry about that, see, but I just worry, I can'nae eat, [name of nurse] the noo as it is, I want tae eat and I cannae eat, och I don't know, but probably a lot oh it's ma head as well, you know what I mean, my thinking, I don't know ... (Paul, interview 1, pages 14-15).

The anger and frustration that he experiences relative to this symptom is evident in his account. When prompted to talk more and describe why he is frustrated, it is apparent that he links eating as having some therapeutic benefit and therefore this may be a way of him striving for health and therefore distancing himself from the threat of death. By being unable to eat, there is a sense that he feels that the threat of death is nearing, that time is running out and if he does not start to eat soon it will be too late and he will not 'recover' - he will die. Such findings may therefore explain why Paul, within the experience of symptom clusters, chooses to talk about this individual symptom in so much detail due to the significance that it holds for him and its association with a fear of death:

Paul: I want tae eat some days but I cannae, I get a wee bit frustrated wi' that, you know, but it's going to take time I

suppose, you know it's like everything else aint it, it's aw doon tae time ...

Roma: Why do you feel frustrated that you can't eat?

Paul: Aye. 'Cause I know once I start to eat, I'll recuperate, I'll recover, I know that. I cannae eat. I want tae eat, I've tried aw the fishes that they had and chicken, in fact they had chicken the other day there, roast chicken and I seen the boys wiring intae it and I was like that, you know that looks no bad that, I don't like the meals in here anyway, they come fae [distant city], right, and they're no very good, right, is that no crazy bringing meals fae [distant city]? Freeze them and then bring them up here and re-heat them, so anyway, the chicken looked no bad, I says "Go and gie us a bit oh chicken wi' a wee drop gravy, that's fine," ... I couldnae get it ower, I says "Ach, I'll need tae leave that," you know that was me finished wi' that, so aye, so it's a wee bit frustrating, you cannae eat, cause I know once I start to eat I'll recover, I know that, actually I weighed maseel the day, I've loast a stone in weight fae I come in here a fortnight ago, I've no had a meal yet, so that's no good either, because if you're no eating you cannae fight nothing, so ... [sighs] ...[pause] (Paul, interview 1, page 16).

8.2.3 Fear of death and coping with symptom clusters

The context of a lung cancer diagnosis and the fear of death which manifests as a result of this also appeared to influence the way that the participants coped with the symptom clusters which they experienced as a results of their cancer treatments. The participants' dependence on such treatments to live combined with their fear of death, at times resulted in them enduring several concurrent symptoms of high severity in order to stay alive. In such instances, the toxic side effects of their treatment, resulting in the occurrence of symptom clusters of high severity, causing much distress and

suffering, were outweighed by the participants' strong desire just to live another day.

The following straightforward quote by Veronica exemplifies this point and demonstrates how after being diagnosed with a terminal illness such as lung cancer, she is only concerned with the bare fundamentals in life. She states that in her situation you only have two choices: you either take the treatment and live, or you don't take the treatment and die. When faced with such decisions Veronica appears to have no concern over the effects of her treatment or what her quality of life will be; the primacy of living appears to surpass this:

Veronica: You either take the chemotherapy and you've a chance o' life or don't take it and you'll die, that's it... (Veronica, interview 1, page 3).

Integral to the some of the participants' accounts was also a sense that despite experiencing symptom clusters of high severity due to their cancer treatments, they appeared to have no limit to what they would tolerate in order to prolong their life. For example, in the extract below, Jessie describes how her treatment was discontinued

by her oncologist due to toxicities that she was experiencing at the time. However, despite this, at her next visit she points out to the doctor that she is *'willing to try anything'*. The use of the term *'anything'* suggests that she has no limits to what she would try and is not bothered with effects of it. As with some of the other participants, in light of being diagnosed with a terminal illness and resultant dependence on treatments, Jessie's main concern is to live and this appears to outweigh the distress associated with the toxic effects of the treatment upon her:

Jessie: He [consultant] says it's making you ill, he said, I think we'll give you a, a couple oh months complete rest fae it, you know ... he says there's no point in making you ill. However, after the first month I got word to come back and see him and I said to the other young doctor that I saw, I said you know I, I'm willing to try anything, so whether he has mentioned that to him, I don't know but I got called in after the one month and he put me onto treatment ... (Jessie, interview 1, page 5).

However, in contrast to some of the other participants and with reference to the above, Dan did appear to have some limits to what he would accept as being worthy of life. His desire to live also appeared to be influenced by his wish to have some quality to his life. The following extract illustrates this point, when Dan talks about his breathlessness:

Dan: Oh aye it's, it's just, that's the kind of stage you're at like you know, what do we do next like, you know ... but what dae you dae next – if you cannae get a ... if you cannae get a breath, Christ you might as well no be here ... you'll no be here, cause it's the breathing that keeps you going, and if you get to the stage that you have to crawl literally? It's nae life ... (Dan, interview 2, page 14).

In summary, this sub-theme has illustrated how, for the participants in this study, being diagnosed with a life-limiting illness such as lung cancer with a high symptom burden, resulted in an inherent fear of death. It also illustrates how this fear of death derived from the context of a lung cancer diagnosis significantly influenced the participants' experiences of symptom clusters. This was most apparent at times when they experienced concurrent symptoms of high severity, which denoted to the participants that the threat of death was nearing. This fear of death within the experience of symptom clusters also appeared to influence the way that the participants understood and made sense of this phenomenon, not choosing to focus on all their symptoms, but tending to pick out salient symptoms based on their symbolic connotations with death. Such findings therefore imply that the participants in this study did not view all of their concurrent symptoms as being of equal weighting but appeared to give those symptoms which they viewed as being symbolic of death greater credence over the others. This fear of death also appeared to influence the way that the participants coped

with the symptom clusters that they experienced as a consequence of their treatment, with them often tolerating severe and debilitating toxicities in order to live another day.

An inherent fear of death was not the only meaning the participants derived from the wider context of a lung cancer diagnosis. The association of lung cancer with self-infliction also resulted in the participants associating an element of stigma with their illness and this, in turn (as with fear of death), also influenced their experiences of symptom clusters. These findings are presented in the section that follows.

8.3 Stigma

The previous section has described how the fear of death experienced by the participants within the context of being diagnosed with a life-limiting illness such as lung cancer, significantly influenced their experiences of symptom clusters.

As stated above, this fear of death was not the only meaning that the participants associated with their lung cancer diagnosis. The association between lung cancer and potential self-infliction also

resulted in many of the participants associating an element of stigma with their illness. As with fear of death, this stigma derived from the context of a lung cancer diagnosis, also influenced the participants' experiences of symptom clusters. In the section that follows, the participants' experiences of stigma are presented in the first instance, prior to the discussion of these findings relative to the participants' experiences of symptom clusters.

8.3.1 Childhood recollections of stigma

The majority of the participants spontaneously discussed issues related to stigma in their interviews and their narratives commonly surrounded their childhood experiences of cancer or the cause of their disease. For some of the participants, feelings of stigma following a lung cancer diagnosis appeared to be influenced by their childhood experiences of cancer where it was stigmatised by society.

In the following example, we see how one of the participants, Dan, recalls a time in his childhood when stigma presented a key lens through which people understood cancer. Here he describes how people would try to avoid having to socially engage with others who had cancer, perhaps in the context of a lack of effective treatments and their probable impending death. There is a sense that people

were angry at others who developed this disease and this may have been related to their fear of the disease and resultant feelings of vulnerability created within them as a consequence of this.

Dan: I mean, at one time if you mentioned you had cancer – Jesus Christ it was like a red rag to a bull ... I, I mean everybody gives you a wide berth, you know that yourself I mean, lets be honest about it like, I mean, eh, you walk doon the street and somebody'll say, "Oh, he's got cancer," Christ you were nearly across the road at one time and I'm talking in older day, I'm not talking, I'm talking when I was a wee boy like, so I'm going really back ... (Dan, interview 2, page 5).

Inherent in his narrative is also a sense that Dan, in light of being diagnosed with a terminal illness, has reflected on his life, and feels embarrassed by his past behaviour towards people with cancer. He tried to distance himself from such actions by pointing out that this happened when he was a boy – a long time ago – at an age when he was not fully responsible for his conduct. He appears to be trying to point out that he is a better person now.

Feelings of stigma were not only evident in the participants' childhood recollections of cancer, but also when they talked about the cause of their disease. Many of them stated that they were or had been smokers, however, evident in their accounts was the way that they

would try and distance themselves from being blamed for their disease, due to fear of potential discrediting. As previously stated, such findings may provide the context to explain why feelings of stigma significantly influenced their experiences of symptom clusters.

8.3.2 Lung cancer: A self-inflicted illness?

The proven causal link between health behaviours such as smoking and the development of lung cancer has been widely reported in the literature and therefore may explain why many of the participants chose to talk about the cause of their disease. A few, like Thomas, openly acknowledged the role that smoking played in the development of their lung cancer.

Roma: Could you explain a bit more about what you mean by that when you say it's an illness?

Thomas: Well, it's a self-inflicted one, I don't know. Lung cancer is a self-inflicted illness, no two ways about that, errr, I've self-inflicted it on me 'cause I've smoked for about 25-30 years and then stopped (Thomas, interview 1, page 1).

Later in the quote he whispers:

Thomas: Err, [whispers the following] I didnae help myself any, as I've smoked for 25 years and I'm what, 50 blah, blah, 58, I didnae help myself any (Thomas, interview 1, page 2).

In the extract above, we also see how Thomas is adamant that he has self-inflicted his lung cancer upon himself and this is implied by the way that he repeats this statement on more than one occasion. However, there is also a sense that he is ashamed that he has caused his illness and this is implied by him whispering the latter quote – as if he does not want anyone else to hear what he is saying. Of significance is that when Thomas said this he was in a private room in the hospital with only himself and the researcher present. This whispering suggests an element of paranoia in Thomas's behaviour at this time and that he fears being discredited if someone else was to hear him admit that he inflicted his lung cancer upon himself.

In contrast to Thomas, even though some of the participants were also smokers, they minimised the role that smoking played in their development of their disease and appeared to dismiss it as a potential cause. This response has been reported elsewhere in the literature and appears similar to the process of 'unrealistic optimism' described by Weinstein (2005), who reported that smokers underestimate their risk of lung cancer relative to both their smoking and non-smoking counterparts.

The most extreme example of this tendency to avoid blame was provided by Veronica, who, despite overtly stating that she smoked, quickly dismissed it as potential cause of her lung cancer and said that it was just down to luck:

Veronica I've never once said "Why me?" Why not me? It's just your Donald Duck, that's it. 'Cause apart frae smoking, I stopped the smoking [...] my cousin [name] he's never smoked a cigarette in his life, I doubt very much whether he's had a pint, very clean living person, you know. His idea of a good night is a fish supper and a bottle of Irn Bru or something like that. Nothing wrong with that, that's his choice, but he's going through hell tae, you know... (Veronica, interview 1, page 11).

In the quote above, we see how Veronica tries to reinforce her belief that her lung cancer was not self-inflicted by comparing herself to a person she knows who never smoked, yet still developed the disease. However, of particular significance is the start of the quote, when Veronica states *'I've never once said "Why me?" Why not me?'* This suggests that Veronica does not want people to view her as being a victim of her disease and feel sorry for her. It may be cautiously inferred that she feels this way as she thinks she does not deserve this concerned reaction from others, as deep down she feels that she has inflicted her cancer upon herself. Therefore, her outwardly denying the potential role of smoking in the development of her lung

cancer may be a way of her coping with this and trying to distance herself from any culpability and potential discrediting.

From the above findings, it is apparent that many of the participants chose to talk about the cause of their lung cancer. What is common to all is the way that they would try and distance themselves from the role that health behaviours within their own control, such as smoking, may have played in the development of their disease. Such findings suggest that the participants acted in this way as they perceived an element of stigma related to their lung cancer and feared potential discrediting if they were linked in any way to the development of their disease themselves. Such feelings of perceived stigma were not only expressed by people who were or had been smokers, but also by one of the participants who did not smoke.

Such findings are reflected in the literature where people with advanced lung cancer perceive themselves to be stigmatised more than other cancer groups due to the strong association with the disease and smoking, irrespective of whether they are smokers or not (LoConte et al. 2008; Chapple et al. 2004). This is exemplified in the following quote from Suzie when she talked about how shocked she

was when she was diagnosed with lung cancer and how she thought it would happen to other people but never happen to her:

Roma: 'Cause you were, you were saying there, you know, you thought it'd be other people ...

Suzie: Mm hmm, mmm mmm ...

Roma ... and not me ...

Suzie Mm hmm ...

Roma Why, why do you think that?

Suzie: I don't, I don't, I really don't know. I'd always eaten well and looked after myself and you think sometimes it happens to people that don't look after themselves and maybe don't eat well and abuse their bodies – smoke; I've never done any of these things and yet it, it .. I think it was more a shock then (Suzie, interview 1, page 2).

In the above quote, in addition to the feelings of shock overtly stated by Suzie, there is also a sense that she feels that her cancer diagnosis was unjust. Such findings may be referenced to the 'just world hypothesis', which states that people believe that they live in a world where people generally get what they deserve (van den Bos and Maas 2009). There is a sense that Suzie feels that her lung cancer was not deserved, as she has '*looked after herself*' as opposed to most people who develop this disease, who, in her opinion, have '*abused*' their bodies. The use of the word '*abuse*' suggests that Suzie associates such people as having maltreated and neglected

their bodies. When referenced to the literature on stigma in patients with lung cancer (LoConte et al. 2008; Chapple et al. 2004), her account suggests that she associates an element of stigma herself related to the role of smoking in the development of lung cancer. There is also a sense that Suzie would have preferred to have developed another type of cancer, one that is not associated with self-neglect. Overall, in her account, it is apparent that she wants to distance herself from the 'stereotypical' person with lung cancer and throughout tries to prove how different she is.

Taking into consideration the perceived stigma experienced by the participants related to the causation of their disease and their childhood experiences of cancer-related stigma, it is understandable that feelings of stigma derived from their lung cancer diagnosis, influenced their experiences of symptom clusters. These findings are presented in the following section of this chapter.

8.3.3 Stigma and the lived experience of symptom clusters

The previous section has provided evidence to substantiate the feelings of stigma that the participants in this study experienced as a result of being diagnosed with lung cancer. Such findings may

therefore explain why such feelings in turn, influenced the participants' experiences of symptom clusters.

As discussed previously, what was noticeable from the study findings was that despite reporting to be experiencing symptom clusters, the participants' narratives would commonly focus on individual symptoms. In this study, this focus on individual symptoms within the experience of symptom clusters appeared to be influenced by the meanings that the person ascribed to a particular symptom. This point is exemplified in the following quotes by Thomas:

Thomas: I must admit I was feeling ... tired ... I started to cough and I was just about sick, I wasnae sick! I wasnae sick, but oh, I wasnae far away fae it and I thought I'd not be able to stop, but no, it cleared up ... but oh, this cough is doing me in ... (Thomas, interview 1, page 15).

Thomas: I'm ... am always wary about this cough (Thomas, interview 1, page 11).

Thomas: ... embarrassing, that I was sitting there spluttering away ... albeit it .. whatever and I've got all these folk round about me and such like wi' this cough, even though you're doing that [indicates covering mouth and nose with hand] ... I think that's more what I was thinking, kinda, that was ... I wisnae wanting tae be ... and everybody felt, I felt as though maybe everybody was looking at me and saying ... look at ... what's he doing in here? ... coughing away like that ... (Thomas, interview 2, page 37).

This singling out of symptoms, within the experience of symptom clusters, was also apparent for those symptoms which the participants associated with feelings of stigma. Individual symptoms such as cough and breathlessness were of particular salience to the participants, as these symptoms were commonly ones that they perceived as being difficult to control and that they could not anticipate. Therefore, such symptoms were viewed as having the potential to attract the attention of others in public places and therefore pose the risk of them being discredited on the grounds of their lung cancer diagnosis. Scambler and Hopkins (1990:1193) describe this type of stigma as 'felt stigma', which is 'a fear of encountering stigmatisation' without any actual experience of stigmatisation. 'Felt stigma' is distinct from 'enacted stigma' where there is actual discrimination against the individual on the 'grounds of social unacceptability or inferiority'.

The participants' narratives focusing on individual symptoms (within the experience of symptom clusters) commonly occurred at times when they were out in public places and their symptom attracted the attention of strangers, resulting in them asking questions about the cause of their symptom. During such episodes, the participants described how they were faced with the dilemma of whether to tell the person that they had cancer or not. The role of control of

information is central to the theory of stigma and social identity (Goffman 1963) as in such instances the stigma is often not immediately apparent and is not known beforehand. Therefore, the person is faced with the dilemma of 'to display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where' (Goffman 1963).

The following extract from Emily exemplifies this finding and traces the links between the context of a lung cancer diagnosis, the resultant stigma and the focus on individual symptoms within the experience of symptom clusters. Of salience is that despite Emily reporting the experience of several symptoms, such as cough, nausea, vomiting, fatigue, dizziness and pain, here we see how her dialogue centres solely on her cough. When referred back to section 8.1.1 detailing the theme of 'Identifying Salient Symptoms', many of Emily's narratives surrounding her experiences of multiple symptoms highlighted her cough as being the most problematic symptom of them all. The significance of Emily's cough to her may therefore be, in part, due to the 'felt stigma' that she associated with this symptom.

In the following excerpt Emily recollects a time when she was in the supermarket and she started to cough, which attracted the attention of strangers around her:

Emily: ... sometimes if I'm in company I get very embarrassed eh, because sometimes there's people there I don't know and they don't know me, I think they think I've got a terrible cold and I shouldn't be out and I'm out causing, spreading germs, just an instance I was in [supermarket] yesterday and eh, I took a coughing fit, standing at the check-out and the woman turned round and looked at me and she just said, "That sounds awful," but I couldn't turn round and say "I know, but it's no the cold, I've got cancer," you know, I says "Och, never mind," and she says "What's wrong wi' you voice?"

Roma: Right ...

Emily: I says "I've got a sore throat," 'cause I wisnae going to stand and say to a stranger, so naturally she would assume, I thought that I had a bad cold ...

Roma: Uh huh ...

Emily: ... and I was maybe there spreading it to other people, so these kind of things, that worries me quite a lot, maybe that's where the nuisance comes in, because depending on how I'm feeling sometimes I don't want to do things where there is company, because of the cough' (Emily, interview 1, pages 8-9).

The above quote is complex and illustrates how Emily's experience of 'felt' stigma in public places focuses solely on her cough, despite her experiencing several other symptoms at this time. What is apparent is that Emily is concerned first and foremost about what people are

thinking of her during such episodes. With reference to feelings of stigma described in the previous sections, it may be inferred that Emily is so preoccupied with the reactions of others because she is scared that people will find out that her cough is not due to a common ailment but that it is due to her lung cancer. She appears to be afraid that she will be discredited if other people find out that she has this disease and this may be due to its self-inflicted nature and its associated poor survival rate. Of relevance is the way that Emily talked about how she re-lived such events for days after they happened, and how such flashbacks would evoke considerable anxiety within her. Such findings highlight how traumatic these experiences were to Emily and the significant distress that they caused.

Complementing such findings is also the way that Emily talked about what her life would be like without her cough, suggesting that if it were socially invisible then her life would be much easier. The way that Emily described her cough as being 'special' suggests that she viewed her cough as being distinct from all the other symptoms which she experienced at that time. Such findings therefore suggest that Emily did not view all her symptoms as being of equal importance, but gave certain symptoms precedence over others,

based on the meaning and perceived impact of the symptom within her life.

Emily: ... if there was no, nobody could see it, nobody could tell me it, this cough is special, nobody can tell otherwise, so if I didn't have the cough ... well, everything else you just need to, like a bad cold, get on with it ... (Emily, interview 1, page 9).

Feeling of 'felt' stigma also resulted in the participants trying to hide their symptoms from others, particularly in public places, in an attempt to conceal their lung cancer diagnosis. As with many of the participant narratives described earlier in this chapter, of interest was the way that they did not try to hide all of the concurrent symptoms that they were experiencing at that time, but tended to only focus on one symptom.

The following quote by Suzie highlights this point. In the following excerpt she talks about how she tried to hide her breathlessness from others when walking up a hill, to avoid people approaching her and asking what is wrong with her. Of interest, is that Suzie also reported to be experiencing several other symptoms at this time such as weight loss, hair loss, vomiting, fatigue and pain.

Roma: ... and you know, what was interesting was when you said, the nurse said to you, stop in the middle and have a rest, and you were saying ...

Suzie: No ... [laughs]

Roma: Can you tell me a bit more about that?

Suzie: No, I just ... [laughs] ... people look at yae and think "What's wrong wi' her?" ... [laughs] I never ... you know, I just carry on, just take my time.

Roma: If you don't mind can you tell me a wee bit more about why, why you feel that, if you were to stop, people would look at you?

Suzie: I know, I know it's daft, no, probably nobody would look at you, but I just feel ... they'd be, maybe looking at you and saying, "I wonder what's wrong wi' her?" [laughs] I know it's daft ... (Suzie, interview 1, page 11).

Such feelings of stigma may stem from a quote made by Suzie, detailed earlier in this thesis, where she talked about how she had led a healthy life, never smoked, and was shocked that she developed lung cancer as it usually happens to people who 'abuse' their bodies, which suggests that she associates an element of stigma related to her disease. Taking this into account, the above quote implies that one reason Suzie does not want to stop is that she does not want to take the risk of people questioning her and finding out about her diagnosis. Instead she adopts other strategies where her breathlessness can remain concealed, such as 'taking her time'. Like many of the other participants, when walking up the hill she appears to be preoccupied with thoughts of what other people will think of her

which is a well known characteristic of the stigmatised person (Goffman, 1963).

Of note and of bearing to these findings, is a point later in her interview, when Suzie described how her breathlessness evoked feelings of anxiety and fear, as she was scared of what would happen to her when she experienced this symptom due to its unpredictable nature and her lack of control over this symptom. Such findings may therefore partly explain why Suzie chose to hide this symptom in particular from all the others that she was experiencing at this time, due to its labile and capricious behaviour, and therefore its significant potential to attract the attention of others in public.

The above section has illustrated how the 'felt stigma' that the participants associated with their lung cancer diagnosis, in turn, influenced their experiences of symptom clusters. This meaning derived from the wider context of a lung cancer diagnosis, appeared to influence the way that the participants understood and made sense of their experiences of symptom clusters, resulting in them picking out individual symptoms (from several that they were experiencing at this time), based on the feelings of 'felt' stigma that

this particular symptom created. Such findings are exemplified in the followings quotes by Jessie:

Jessie: But eh, that's my main reason I think, I feel if I'm eating I'm no going to lose too much weight and I'm no going to get "thin, thin" and ... but my sister will say that to me, she'll say, "I mean anybody looking at you would never know there was anything wrong wi' yae like that" and I ... I mean I see people that have it, that look really bad, you know, and I think oh, I don't want to get like that ... I'll just ... I'll eat my food just as much as I can, as well as I can .. you know [laughs] ... But as I say, it might no be solely the, the food, I don't know ... that makes them thinner, I think it is ... I think it's 'cause you don't eat you get thinner, you know ... but eh ... I just assume it's that, but em, otherwise we're awright. I mean you, you can go up to the clinic and ... sometimes see them, they're like that [indicates a thin person] ... you know, they're really just so thin and fragile-looking (Jessie, interview 2, page 27).

Jessie: I, I just have this feeling that em ... well, you, you most folk that have cancer go thinner and thinner and thinner don't they? So I just feel if I eat, its going to prevent that [starts to laugh] ... well maybe no prevent it, but it'll help it, if it ... I mean if you don't eat you're going to get thinner, anyway I don't know if its that on its own or if it's the cancer as well that makes you thinner or its just the no eating that makes you thinner, but I just feel as long as I, as my appetites no too bad, I'm quite happy, you know ... I'm quite happy about that. (Jessie, page 26, interview 2)

Jessie:... I'm hardly skinny so, I'm doing awright, I'm no losing much weight (Jessie, interview 1, page 16).

Such findings (as with the previous sections presented) therefore highlight the core role that context and meaning play in the

experience of symptom clusters in patients with advanced lung cancer.

8.4 Conclusion

This chapter of this thesis has presented the super-ordinate theme of 'The role of context and meaning in the lived experience of symptom clusters'.

In the first instance, this chapter illustrates that the participants in this study did experience symptom clusters and that they did perceive there to be associations between the symptoms that they experienced. Furthermore, the findings presented also denote the occurrence of core symptoms which commonly feature in the experience of symptom clusters in patients with advanced lung cancer (fatigue, cough, pain and breathlessness) and, in turn, describes the symptoms that these core cluster symptoms commonly concurred with.

In addition, the findings also illustrate time points where the occurrence of symptom clusters in patients with advanced lung cancer are most prevalent, which in this study was throughout

treatment phases. Complementing such results is also the information detailed in this chapter regarding the nature and pattern of symptom clusters experienced by the participants in this study, with clusters experienced during treatments often being transient in nature, and others remaining constant throughout the patient pathway. However, of particular significance to this thesis is the way that the participants in this study did not appear to view all the symptoms that they experienced in the same way, but did appear to highlight salient symptoms based on the meanings that they ascribed to them.

Relative to the fear of death, the influence of this context on the participants' experiences of symptom clusters manifests itself in a number of ways. For some, this fear of death was most prominent at times when they experienced concurrent symptoms of high severity, which denoted to the participants that death was nearing. This fear of death also influenced how the participants coped with the symptom clusters that they experienced as a result of their cancer treatments, with them often tolerating distressing and disabling symptoms in order to live another day. This fear of death, within the backdrop of the experience of symptom clusters, also appeared to influence the way that the participants understood and made sense of the multiple symptoms that they were experiencing. Many of their

dialogues would focus on individual symptoms despite them experiencing several at this time, and this focus on individual symptoms appeared to be related to the meaning that they ascribed to these symptoms, which, in this study, was commonly a fear of death. Symptoms such as breathlessness, lack of appetite and weight loss were commonly highlighted by the participants from all the rest that they were experiencing and this may be due to the fact that all of these symptoms reflect the basic physiological functions required to maintain life.

As well as fear of death, the participants in this study also associated an element of stigma related to their lung cancer diagnosis, and, as presented above, this may have been due to the perceived self-inflicted nature of their disease. This context of lung cancer related stigma, as with fear of death, also appeared to permeate the participants' experiences of symptom clusters. As was apparent, relative to the context of fear of death, was that amidst the experience of symptom clusters, the participants would commonly choose to focus their narratives on only one symptom. This symptom was often selected based on its potential to attract the attention of others in public places and therefore pose the risk of the individual being potentially discredited based on the grounds of their lung cancer diagnosis.

Therefore, the findings presented in this chapter highlight that the experience of symptom clusters in patients with advanced lung cancer is a highly contextualised experience which is deeply embedded in meaning. The results suggest that people with advanced lung cancer use the context of their illness and the meanings derived as a means of understanding and making sense of their experiences of symptom clusters, by creating an hierarchy of symptoms, choosing to focus on individual symptoms that are most meaningful to them in their lives. Therefore, having presented the super-ordinate theme of 'The role of context and meaning in the lived experience of symptom clusters', the following chapter will present the second super-ordinate theme of this thesis which is entitled 'Symptom clusters and loss of sense of self'.

Chapter 9 Symptom clusters and loss of sense of self

9.1 Introduction

The previous chapter has detailed the super-ordinate theme of 'The lived experience of symptom clusters and the role of context and meaning'. This chapter follows on and presents the findings of the second super-ordinate theme derived from this study which is 'Symptom clusters and loss of sense of self'. This super-ordinate theme is informed by three sub-themes: 'The impact of symptom clusters on the self', 'Being a burden', and 'Trying to maintain a coherent and valued self'.

This super-ordinate theme is used to illustrate the 'knock-on' effect of the experience of symptom clusters on the participants' lives, and how this often manifested itself in a loss of sense of self. It highlights how this loss of sense of self was closely followed by feelings of being a burden at the dependency on others created by the many symptoms that the participants were experiencing. However, it also demonstrates how the participants, in light of this assault on their sense of self due to the symptoms that they were

experiencing, employed various strategies in a bid to try and maintain a coherent and valued sense of self.

9.2 The Impact of Symptom Clusters on the Self

In the interviews several of the participants talked about the limitations placed on their lives due to the symptom clusters that they were experiencing and how this impacted on their sense of self. On analysis of the data, what became apparent was the different ways in which the experience of symptom clusters contributed to the loss of sense of self that they experienced.

For most of the participants, their loss of sense of self relative to the experience of symptom clusters was related to their inability to undertake many of the taken for granted roles and activities that they occupied in the past. This in turn impacted on their sense of self, as they observed *'their former self-images crumbling away without the simultaneous development of equally valued new ones'* (Charmaz, 1983: 168).

Of particular significance to the study of symptom clusters in patients with advanced lung cancer, was how the participants' dialogues

surrounding their loss of sense of self would often focus on one symptom, despite them reporting to be experiencing several concurrent symptoms at this time. This symptom was often the one which significantly impacted on their level of physical functioning. This focus on individual symptoms in the presence of symptom clusters is a common theme derived throughout all the superordinate themes presented in this thesis, and the implications of such findings are discussed in greater depth in this chapter and the discussion that follows.

For many of the participants, their dialogues surrounding their loss of sense of self commonly focused on the symptom of fatigue. This symptom appeared to be selected from all the other concurrent symptoms that they were experiencing as it prevented them from carrying out many of the roles and activities which they undertook prior to their cancer diagnosis. The impact of this symptom relative to the loss of sense of self experienced by the participants is probably best exemplified in the following quote by Thomas. It conveys the significant impact that his fatigue had on his life.

Thomas:... just I feel I'm always, I feel tired aw the time. Now, I was never ever like that, I could go on for hours and hours and hours, but now I feel as though if I do something ...

I want to sit down and close my eyes ... (Thomas, interview 2, page 12).

In the above quote, it is evident that Thomas's fatigue was ever present and did not diminish. It resulted in considerable restrictions being placed on his life and resulted in him being unable to function at the level that he had become accustomed to prior to the onset of his illness. This, in turn, appeared to impact on his sense of self, as he felt that he was a different person to the one that he was in the past. Such findings were of particular significance to Thomas, as in his interviews he described how within his family and social circle he was viewed as being the 'handyman'. He was the person they would go to if they needed help to fix appliances or do various DIY jobs around the house. However, in light of the symptoms that he experienced and the resultant physical limitations, he also spoke about how he could no longer maintain this role in his life. This, in turn, manifested itself in feelings of anger and frustration, as he wanted to help his friends and family but couldn't.

This point is further exemplified by comparing the way that Thomas spoke about some of the other concurrent symptoms that he was experiencing. In the quote below, we see how when he talks about the symptom of nausea, there is no mention of the impact of this

symptom on his sense of self. He describes his nausea in a matter of fact way, and does not appear to be bothered by it. This in turn may be due to the fact that this symptom did diminish, unlike his fatigue which was ever present.

Thomas:... I was just about sick, I wasnae sick! [Someone enters the room] Oh, come in, errr.... I wasnae sick, but oh, I wasnae far away fae it and I thought I'd not be able to stop, but no, it cleared up and that was it ... (Thomas, interview 1, page 15).

Suzie also singled out the symptom of fatigue from all of the other symptoms that she was experiencing at that time, due to the significant restrictions it placed on her life since being diagnosed with lung cancer. In the following excerpt we see how her sense of self has dramatically changed due to the impact of fatigue on her life.

Suzie: Just lifeless really, you know ... falling asleep all the time, just wanting to go to your bed and I wouldn't give into it to begin with then I thought this is silly, it's actually your body telling you to rest and I used to go down for a wee nap in the afternoon, slept all night [slight laugh] ... but I was, I felt guilty going to bed, because I was never one for going to my bed in the afternoons or during the day, but I had to do it.

Roma: And what, what ... and why do you think you felt, you felt guilty about going to bed?

Suzie: Because I had never ever done it before, I don't, I don't know, just felt I shouldn't be in bed during the day, it's hard to ...

Roma: Can you, if you don't mind can you tell me a bit more about why you felt you shouldn't be in bed during the day, is there anything that's made you think that way?

Suzie: No, I just feel bed's for night time and you're lazy if you go to bed [laughs] ... I was never one for, you know I was always on the go, probably felt guilt because I was always on the go and then couldn't do it, it might sound daft, but ...

Roma: No, no ... and, and you were saying there as well, you didn't want to give into it at first ...

Suzie: Mm hmm. I thought, if I don't give into this, it'll be fine, I'll get over it, but you can't, you've got to give in, cause your so tired ... (Suzie, interview 1, page 5).

Suzie's narrative has demonstrated how her fatigue was all-consuming with her sleeping most of the day and night and doing little else. Her use of the term 'lifeless' indicates the profound loss of sense of self that she experienced at this time and was opposite to the active persona that she described herself as being in the past. As was common with Suzie throughout both of her interviews, the perceived stigma that she associated with her lung cancer diagnosis appeared to influence her symptom experiences. The main reason that she tried to resist the impact of fatigue upon her appeared to be due to a fear of potential discrediting by others who may have viewed her as being 'lazy'. When she did eventually give in to her fatigue, of interest is the way that Suzie appeared to blame her 'body' by stating '*it's actually your body telling you to rest*'. By doing this it may be inferred that Suzie intentionally made this statement to displace any

blame from her 'self' for sleeping all day and therefore reduce the risk of potential culpability.

As with Thomas, we can see in the quote below that the evident distress and loss of sense of self that Suzie associates with her fatigue, does not appear to be apparent in her experiences of other concurrent symptoms such as hair loss. In the quote below, in comparison to the way that Suzie talks about her fatigue and the way that this symptom impacts on her life and her sense of self, we see that in her dialogue below concerning her experiences of hair loss does not afford the same level of detail. Furthermore, what is evident is the way that she appears to minimise this symptom and does not appear to be unduly upset by its occurrence.

Roma: Is it OK if we go back and have a wee, just to ask you a few things about them, just when, you know, you were saying that, that your hair came out, can you tell me a wee, wee bit about that, about how you felt when that was happening, or .. ?

Suzie: Well, it wasn't too bad, it was only coming out when I was combing it, I've heard people saying that, you know, when they get up in the morning it's been lying on the pillow, but I didn't have anything like that, it was just patches all over but I wasn't completely bald ... but eh, my, my hair was always a bit fine anyway, I always had very, very fine hair, but as I say it wasn't too bad, it was coming out when I used to comb my hair ...

Roma: ... and how did you find losing your hair? How did you feel when that was happening?

Suzie: Well, I just hoped that I wouldn't go completely bald and I didn't ... mmm mmm ...

Roma: Mmm, were you thinking anything else, or ... ?

Suzie: No, no ... (Suzie, interview 1, pages 21-22).

The contrast in the two quotes detailed above provide further evidence to demonstrate how within the experience of symptom clusters, the participants did not view all their symptoms as being of equal weighting but paid particular attention to those which had a significant impact on their sense of self.

Such findings were also reflected in Dan's narratives. For Dan, despite experiencing several concurrent symptoms such as cough, breathlessness, lack of appetite, weight loss and fatigue, it was the symptom of breathlessness which was the focus of much of his narratives surrounding his loss of sense of self. Dan's breathlessness was central to his experience of lung cancer, and he afforded much time and detail in both of his interviews to talk about the impact and significance of this symptom in his life. In the following excerpt we see how simple, previously taken for granted, everyday activities were compromised due to his breathlessness:

Dan: Well, I was always, I was always ... I, I could walk in that back door, walk to the shed, cut the grass, go to the caravan, get the water, wash the caravan and wash three motors and the caravan in an hoor, now it would take me an hoor to walk to the shed and fill the pails noo, never mind washing them because you just don't have the breath, your intake of breath. OK your lung's full oh cancer, we know that, but your intake oh breath isn't enough, it's like the day, what you want tae dae so you're within yourself a percentage angry wi' yoursel if you like because no being able tae dae what you did before that, you know your, your mind disnae go back and say, 'Christ I cannae dae that noo,' your mind goes forward and says 'I'll still dae it,' ... you know, it does, well mine does anyway... (Dan, interview 2, page 13).

At the start of the quote, Dan appears to be bragging at how much he could do in the past, and this may have been a way for him to try and reclaim a sense of the person he was before he was diagnosed with lung cancer. There is a sense of underlying sadness when he talked about how he could no longer carry out these activities and this may have been because he knew that there was all likelihood that he would never regain this level of functioning again. Of significance is the evident disharmony between Dan's body and mind at this time. His mind appeared to want to do things, but his failing body couldn't, which resulted in heightened feelings of anger and frustration. This occasion was not the only time that Dan appeared to make this distinction from his body and his mind, often at times when his symptoms were severe. It may be inferred that Dan used

this body and mind disassociation as a way of coping with his symptoms in order to try and regain a sense of control. He may have felt that if he can't control his body, he could at least control his mind.

The contrast in the way that Dan talked about his breathlessness compared to the other symptoms that he experienced at this time (as with the other two participants detailed above) is also apparent. In the following quote he talks about his gastritis. Compared to his breathlessness, which he describes in vivid detail as significantly impacting on his level of functioning and sense of self, we see how he does not associate the same level of significance to this symptom, with no mention of its impact on his sense of self. This in turn may be due to the fact that his gastritis was being successfully managed whereas his breathlessness, which he describes throughout both interviews as being hard to control, was instead unpredictable and resulted in an innate fear of death:

Dan: My stomach's no really been right since December, no in pain, you know but it goes like a furnace if you like, at times. The bottom oh your gullet and your stomach it's, it's no indigestion, as you know, it's, it's really burny eh, so they've gave me tablets for that which has actually cured the, the symptoms, if you like ... (Dan, interview 1, page 13).

The above findings have highlighted the loss of sense of self experienced by the participants due to the symptoms that they were experiencing. Of significance to the study of symptom clusters in patients with advanced lung cancer is that despite experiencing several concurrent symptoms at this time, the participants' narratives surrounding their loss of sense of self appeared to focus on only one symptom. This symptom appeared to be of particular significance to the participants due to its impact on their level of physical functioning, leading to significant restrictions being placed on the activities that they could undertake, ultimately impacting on their sense of self.

Relative to the experience of symptom clusters and loss of sense of self was also the way that some of the participants spoke of times when they experienced several concurrent symptoms of high severity which resulted in them no longer recognising themselves. Such findings can be referenced to the work of Corbin (2003) on 'The Body in Health and Illness' where she writes about 'knowing one's body' and refers to Merleau Ponty's work on the 'Phenomenology of Perception' (Merleau Ponty 1962) when stating that the body is 'the embodiment of who we are. The self becomes what it is through the

body. The body is the self's representative of the world' (Corbin, 2003: 258).

This point is exemplified in the following quote by Richard who experienced several concurrent symptoms of high severity due to his radiotherapy treatment and recalled how 'awful' he felt at this time (see section 8.1). Of salience to Richard is another point in his interview when he recalled how 'bad thoughts' came into his mind when receiving this treatment. When asked to explain this term, he described how such thoughts stemmed from a fear that his radiotherapy would not work and he would die of his lung cancer. This fear was based on his experiences of his father dying of lung cancer, who, like Richard, received radiotherapy treatment but died soon after from his disease. Therefore, at the back of Richard's mind during this time was a fear that he would follow in his father's footsteps.

Roma: I mean, you were telling me how you were feeling there at the end of your radiotherapy and you said, you said ... and when you finished you felt awful ...

Richard: Awful, really ...

Roma: ...and you were telling me how you felt ...

Richard: Aye.

Roma: ... at that time. Is there anything going through your mind at that time, when you were feeling that way?

Richard: No, no ... eh, the only way I can describe it as ... my body was blank, so was my mind, I just ... I went up the stair to my bedroom and stayed there, just didnae come oot and then I said the last week oh the radiotherapy, when I went up to my, the bedroom and stayed there, I didnae get oot till I was going back for more radiotherapy and then after I was finished, I must have been up the stair a week, at least a week before I came back doon – awful, no reading the paper, no watching television – nothing, I just couldnae be bothered doing anything ... I would really say that, that was a really horrendous period, terrible, absolutely terrible ... (Richard, interview 2, page 13).

The profound distress experienced by Richard after his radiotherapy treatment is evident. His narrative suggests that the concurrent symptoms that he was experiencing at this time were so severe that he experienced a total loss of sense of self and this is intimated by the way that he stated '*my body was blank, so was my mind*'. There is an underlying sense that this experience traumatised Richard as he no longer recognised himself and feared what would happen to him as a consequence. In response to such events, Richard hid himself away in his room doing very little, and there is a sense that he stayed in there, waiting for his sense of self to return.

Emily had similar recollections to Richard and in her interview described how her sense of self was severely compromised when she

underwent radiotherapy treatment. During this time, she experienced concurrent symptoms which caused significant debilitation, resulting in her barely managing to perform the most basic activities of daily living. The profound tiredness that she experienced due to her treatment is apparent, and this appears to be exacerbated by the other concurrent symptoms that she is experiencing, such as sickness and feeling depressed. Of pertinence to this thesis is the way that she states that she felt as *'if my body wisnae my own'* which implies that her body was unfamiliar to her due to the impact of her symptoms upon her self. There is an underlying sense that Emily felt that if such episodes were transient, and not constant, then she would have been less distressed by these events in her life.

Roma: What was the tiredness, how would you describe it when you were ... ?

Emily: Well, I just felt, as if my body wisnae my own and night was coming into day ... if I could come to myself for a wee while in between, but it was more like, I had a, I mean I wis sick ... I just wanted to sleep all the time and I think that was depressing me, because I was hoping that when I got the, the chemotherapy, the rad., the radiotherapy, sorry ... that eh, I would get there and get it and come back and that'd be it till the next time ... (Emily, interview 1, page 73).

Such findings are further elaborated in the following quote by Emily, when she explained why she felt her *'body wisnae my own'* during such times:

Roma: Em, and you described, described, when you were talking about that, you said it's as if your body's not your own,

Emily: Uh huh, uh huh

Roma: Can you just explain a wee bit more about ...

Emily: [slight pause] Eh, well I think it's because you, you're find, you're finding it quite difficult to do a lot of the things, or most things, because all you want to do is try and sleep and even if you're not sleeping you just feel drained, you don't, you don't want to, or you don't feel that you've got to get up, it's an effort to go to the toilet. I don't know what makes you feel like that. Apart from your getting the radiotherapy, I don't know, I don't know what part oh it makes you feel like that, luckily again, it disnae last forever.

Carer: It wis every day for a month, a month though, wis'nt it?

Emily: Mm hmm.

Carer: So it takes a lot out you, going away into the [place name] all the time and coming back and, every day ...

Roma: Yeah.

Emily: Oh, I suppose all these things, they just, that's what I mean, you don't feel like yourself. Sometimes I often wonder if I ever will feel myself years ago, I really don't know whether [laughs], eh, I would know how I felt for years to go for me, if it came and hit me in the eye ... (Emily, interview 2, page 56).

In the first instance, the unfamiliarity of her body at such times appears to be due to the incapacitation that Emily's multiple symptoms create, which make even the most basic of physical functions such as going to the toilet an effort. Within the quote, it is also apparent that Emily tries to find some comfort in what is happening to her by reassuring herself that such episodes do not last forever and that they are to be expected due to the frequency and duration of her radiotherapy treatment. However, the remorse and sadness which accompanies such experiences is evident, and this appears to be primarily due to her fear that she may never regain her sense of self again. Such feelings were of particular pertinence to Emily, as throughout her interviews she talked about looking forward to 'the good bits' - the short periods in her life when she could live without the burden of illness and feel more like herself 'from within':

Roma: And, and what do you mean by that when you say, you know, 'start getting more like yourself', can you explain a wee bit about what that means?

Emily: Well, I'm more like myself from within ... that's, that's part oh it over. Eh, and now I can get into the good bits, the wee times, the short times I've got in between something else cropping up and you're no looking for around the corner 'cause you not ... you just think you're grateful to feel better and you just want to try and do a wee bit more things that you couldn't do when you were unwell., when you felt unwell. Sometimes that disnae last for very long and then something else comes along... (Emily, interview 2, page 3).

This quote illustrates the pattern of illness in Emily's life – the bad times followed by the good. The liberation offered by the '*good bits*' is evident and appears to have resulted in Emily living a less restricted life and being able to do things that she couldn't in the past. Linked to this is her perceptions of her sense of self at this time; feeling '*more like myself from within*' suggests that her sense of self was regained in absence of symptoms of high severity, when she was able to recognise her body once again. The quote also suggests a link between the body and wellbeing; the more that Emily recognised her body, the better she felt.

The previous section presenting the sub-theme of 'The impact of symptom clusters on the self' has demonstrated the core role that the experience of symptom clusters played in the loss of sense of self experienced by the participants. Of particular interest to this thesis, is the way that despite the participants experiencing several concurrent symptoms at this time, most of their dialogues surrounding their loss of sense of self, focused only on one symptom. This symptom in particular appeared to be sentinel to their experiences of loss of sense of self, due to its significant impact on the individual's level of functioning which in turn limited any activities that they could undertake. It also illustrated the role of the body in relation to the concept of the self, how at times when the participants

experienced concurrent symptoms of high severity, their body, which they had become accustomed to, became unfamiliar, which in turn severely compromised their sense of self at this time.

Related to the loss of sense of self experienced within the context of the experience of symptom clusters was also the way that many of the participants talked about how they felt they were a burden due to the dependency that their multiple symptoms created on others. This link is presented in the following section which details the theme of 'Being a burden'.

9.3 Being a burden

According to Charmaz (1983), being a burden 'essentially involves becoming more dependent and immobilized' and 'follows closely upon loss of hope and loss of recapturing positive self images of the past' (Charmaz 1983:118).

Apparent in many of the participants' interviews were feelings of being a burden due to the symptom clusters that they were experiencing, as they now relied on their carers to undertake many of the functions and roles that they themselves occupied in the past.

Inbuilt in many of their dialogues were feelings of frustration, as they wanted to maintain these roles but couldn't.

Feelings of being a burden were of particular importance to some of the female participants. Their inability to maintain traditional roles such as cooking and cleaning due to the multiple symptoms that they were experiencing often resulted in their male partner taking on these duties. This in turn manifested itself in feelings of guilt and being a burden as they felt that it was their duty in their marriage to carry out these roles.

This finding is demonstrated in the following quote by Jessie who was significantly debilitated by the multiple symptoms that she experienced such as breathlessness, lack of appetite, hair loss, fatigue, nocturia, headache, pain, constipation, and insomnia. In the following quote, she talks about how her husband now does all the housework and the guilt that she feels as a consequence of this:

Roma: I mean, you've mentioned feeling guilty, just, you know a couple of times there ...

Jessie: Uh huh, aye.

Roma: ... em, if you don't mind can you tell me why, why you think you feel guilty? Can you explain that a wee bit more to me?

Jessie: I think it's just in my nature to be like that, em ... I would think, wouldn't it?

Carer: Aye, you just feel that you should be dain these ...

Jessie: I just feel I should be ... aye, I should be ... aye, I should be, it was like ... it, I mean even before I was ill in any way eh, I wouldnae lie in bed long – no because I had to get up for anything, I would have felt guilty if I had lain and I mean – that's daft, that's, that's crazy, but I would say oh no, I better get up, that's no good lying in your bed ... aw, aw naw you cannae dae that, but I think it's ... as I say it's just in my nature, I just ... I see [name of husband] doing this housework and I know I should be doing it; if I was able I would it, but eh ... that kind of thing it makes me ... I feel guilty, I really do. That's awright for a couple oh weeks but when it goes on and on it's ... it's quite, you know, quite a bit, but as I say I think it's just, a lot oh my make-up [personality] is like that em, I would feel guilty anyway [laughs] ... eh ... I don't know ... I don't know why else I should feel guilty about it, but I do and that's just daft, 'cause [name of husband] does ... I know [name of husband] disnae mind doing it fur me, he's no doing it wi' a grudge ...

Carer: No, I ...

Jessie: ... he's doing, he does it quite willingly but if it was somebody that was doing the thing and was really ... you know didnae want to do the ... you know and let you know they didnae want to do it ... well that would be ... that would be terrible, I couldnae live like that no ... I couldnae ... [laughs] ... I couldnae live like that, but ... you wonder how folk get on that are on their own ... (Jessie, interview 2, pages 27-28).

In the above quote, Jessie appears to be upset at her dependency on her husband because it is not in her 'nature' to act in her way. There is an underlying sense that she feels that her incapacitation has been

forced upon her, and she is angry at this, as she can no longer fulfil her role as a wife. She appears to try and salvage a sense of the person she was in the past, by reflecting on the active person she was before her illness, and she appears to find comfort in this, reassuring herself that she is not acting in this way based on her own volition. There is also a sense that the guilt she feels as a result of her husband now undertaking many of her roles is worsened as it is now a constant occurrence with her progressing condition. However, her feelings of guilt at the same time appear to be diminished as she feels that her husband does not grudge helping her but does it willingly. Her use of social comparison also helps Jessie reflect on her circumstances and come to the conclusion she is better off than others in a similar condition.

Linked to such findings is also the way that some of the male participants tried to minimise the burden of their cancer on others by concealing the multiple symptoms that they were experiencing. Of relevance to these male participants was the way that they often talked about their family in their interviews and described how, as a father, they felt that their main role was to provide for them and protect them from any harm. The quote from Richard below best exemplifies this finding:

Richard: ... I've just been positive the whole way through, obviously for my family as well, don't let them see, don't get me wrong there's been days when I've been really down wakening up in the morning and coughing and spluttering and getting up and being breathless, I didnae let them see me like that I let them see the jolly side and they've seen that the whole way and it's helped them, it's helped my family ... (Richard, interview 1, page 5).

Throughout his interviews, Richard talked a lot about how he had adopted a positive attitude and how this had helped him cope with his illness. To him, being positive had some therapeutic benefit which he felt helped in his fight against cancer. However, from the quote above, it is evident that the adoption of a positive attitude had another meaning for Richard. To him, being positive was also a way of concealing the myriad symptoms that he was experiencing from his family, often to the detriment of himself.

The above findings have described the profound loss of sense of self experienced by the participants due to the symptom clusters that they were experiencing. It has also described how this loss of sense of self experienced by the participants was closely followed by feelings of being a burden to others. In an attempt to try and adapt to this loss, the following section details the third sub-theme 'Trying to maintain a coherent and valued self'. This sub-theme describes the strategies that the participants employed to try and recapture

some element of their past lives and build their self esteem in light of their sense of self being compromised due to the symptom clusters that they were experiencing.

9.4 Trying to maintain a coherent and valued self

As stated above, this section of this thesis describes the strategies used by the participants to cope and adapt to the loss of sense of self that they experienced as a result of the symptom clusters that they were experiencing. It details how many of the participants used the process of downward social comparison to reassure themselves that there were people who were worse off than them in the world. The section also illustrates how many of the participants strived for normality, to capture elements of their life that were at threat or had been lost.

9.4.1 Comparing themselves to other people with cancer

Within the experience of symptom clusters and loss of sense of self, many of the participants used a strategy of downward social comparison in order reassure themselves that there were others who were worse off than them. This strategy appeared to help them build self esteem and create positive perceptions of themselves.

The types of social comparisons made by the participants appeared to be influenced by their gender. For the female participants, the comparisons that they made were often between themselves and people who were younger than them. This may in part have originated from the natural female instinct to protect their young. This is best illustrated in the following quote by Jessie who talked about how she felt sorry for 'these young folk':

Jessie:... you never ever sort of imagined you'd get to that stage and yet I mean, at the same time I say to myself you're s..., I'm only 71, so I thought well, you're lucky, I mean there's some young folk don't get to 21, by God, and they have cancer, that's the ones I really feel sorry for. I mean I feel, I've had a life ... you know, and we've, we've done lots oh things haven't we, been lots oh holidays and had good times and I don't regret anything at all. Em, but these young folk ... oh, I think that's awful sad, really terrible that they, they've no had any life at all and they're going through aw this, you know ... (Jessie, interview 1, page 7).

In the first instance, it is evident that being in such an incapacitated state was never in Jessie's anticipated life biography. There is an underlying sense of sadness and at the same time shock that she had come to a stage in her life when she could no longer undertake many of the roles and activities which she had become accustomed to in the past. Although she was 71, there was a sense that Jessie felt that she was too young to be in this incapacitated state and had lots

of things in life that she still wanted to do. In order to cope with such thoughts, she used the process of downward social comparison and compared herself to younger people who had died of cancer, stating that she had at least 'had a life'. This, in turn, appeared to make Jessie reflect on her life and find comfort in her conclusion that she had had a good life.

In contrast to Jessie and some of the other female participants, the male participants in this study appeared to use social comparison in a different way in a bid to recapture their sense of self that had been fractured due to the symptom clusters that they were experiencing. The male participants would often compare themselves to other people with chronic illnesses, and focus on their physical attributes, commonly coming to the conclusion that they were fitter and better than them. This is exemplified in the following quote by Dan when he described a time when he was in hospital and compared himself to other people with cancer who were in his ward:

Dan: I've had my eyes opened in the last year, when you're looking about you, I mean I was lying in, I ended up in a ward after the biopsy eh, six oh us and I can assure you I was the healthiest oh the six and I'd just come oot an operation so when you're looking about yae, yae keep saying to yoursel – I'm no bad and I always say that tae, cause there's always somebody worse just next tae yae, and I mean you get into

they, you get the em, clinics in [name of hospital]. Pre-ch..., pre-chemo clinics if you like and you're looking roond about you and you're saying to yourself – my God like, you know and I'm complaining ... (Dan, interview 1, page 17).

The above quote highlights how this was a new experience to Dan and one that he had not encountered in his life before. This, in turn, may explain why there is a sense that Dan was scared at what he saw around him and why he felt the need to convince himself that he was different from the rest. It is evident that he came to the conclusion that he was 'the healthiest' patient in the ward, based only on the outward physical appearance of the others. He may have done this because it was the only information that was available to him with which to make such comparisons. When claiming that he was the fittest, he tried to convey to the researcher that there was no doubt in his mind that this claim was true. However, there is an underlying sense that he actually did this to convince himself that his claims were true as well.

Paul appeared to adopt a similar strategy in trying to maintain a coherent and valued sense of self. Like Dan, he based his social comparison on the visibility of the outward physical attributes of others:

Paul:...you say to yoursel, "God's sake," you know, and you see other people and they're infirm and they cannae walk and they've got amputees up there on that ward as well and, I'm like that, there is a bit oh hope for me, well there's hope for them as well, but some oh them cannae handle it, you know and you hear a wee wuman she's greeting during the night and I says "Who's that, is that a wuman's voice?" 'Cause this other guy was, "Aye she, she's doon in another ward there, she cannae accept that she's loast her leg, right" ... (Paul, interview 1, page 11).

In the process of downward social comparison, of interest is the way that Paul viewed people with obvious physical impairments as being worse off than himself, despite being diagnosed with a terminal illness. When related to the feelings of stigma expressed by the participants in the previous chapter on 'The lived experience of symptom clusters and the role of context and meaning', it may be inferred that Paul viewed these conditions as being worse as they were overtly visible and his cancer was not – it was hidden. Such findings may also be related to the following section on the role of 'normality', where Paul talked about how he commonly bracketed off thoughts of cancer in order to cope with his illness. It may be proposed that if he had outwardly visible manifestations of his disease then it would have made this process of achieving normality much harder.

As well as using the process of downward comparison in an attempt to regain their sense of self which had been compromised due to the symptom clusters that they were experiencing, many of the participants also spoke about how they strived to achieve a sense of 'normality' in their lives. To most, normality described the state of their lives before they were diagnosed with cancer. Accessing parts of 'normality' appeared to assist the participants in their attempt to try and regain a valued and coherent sense of self. This is detailed in the following section.

9.4.2 Normality

Many of the participants talked about 'normality' in their interviews. For most this was a term that they used to describe the states of their lives prior to being diagnosed with lung cancer. The main reason that the participants appeared to strive to access normality was to regain a sense of the person they were before their illness. For many, normality was reached when they could undertake roles and/or activities that they were accustomed to in the past – many of which had been fully or temporarily compromised due to the symptom clusters that they were experiencing. What was also apparent was the evidence of feelings of positivity and wellbeing which accompanied such times when they could access elements of their 'normality'.

Some of the participants accessed normality, by 'bracketing' the impact of their illness on their lives. According to Bury (1982), people do this in order to cope with their illness so that its effects on the person's sense of self remain relatively slight. For two of the participants, Paul and Flora, their striving for normality had much in common with the above. Paul, in the following quote, talked about how he tried to not to think about cancer:

Paul: I don't really think about cancer noo, I just put it tae the side, it's something that I've got and I don't think about it till I need tae get medication or something like that, that's the only time I think about the cancer, other than that I just have a normal day, because I believe if I had to go the other way and out on a negative thing, well ... you're only going tae depress yoursel, you'd sit in the house and wouldnae go out ... (Paul, interview 1, page 2).

Paul appeared to try and live a 'normal' day by bracketing off unpleasant and unwanted thoughts regarding his lung cancer. His dialogue suggests that he did achieve this state of normality most of the time. However, this appeared to only become problematic when he had to take medication, implying that when he experienced symptoms he found it hard to erase the reality of having cancer from his conscious thought.

As previously stated, for many of the participants, a return to normality was signified by being able to do things they were accustomed to in the past. What were also evident were the feelings of wellbeing and positivity that accompanied this return to this state. This is best exemplified in the quote below by Suzie who expressed overt joy at feeling well again. Such heightened feelings may, in part, have stemmed from the extreme fatigue that Suzie experienced when receiving treatment, which prevented her from performing even the most basic of tasks. In light of such experiences, Suzie appeared to re-evaluate her life, resulting in an appreciation of the simple things in life that she once took for granted:

Roma: And when you, you know you were saying there it's good to feel well again ...

Suzie: Mm hmm ...

Roma: ... can you describe ...

Suzie: Just I can do things now, do things about the house and go for a walk, go round shops, go out in the fresh air, just ... trying to get back to normal.

Roma: Oh, and ... but when you say normal ... what do you, what, what do you mean by that? What, what's normal to you?

Suzie: Just feeling well and being able to do things, you know ... the simple things in life! – like going for a walk, mmm mmm ...

Roma: And how do you feel being able to do these things now?

Suzie: I think it's great, I think it's wonderful, I really do think it's wonderful (Suzie, interview 1, page 4).

Similar feelings of joy were also expressed by Emily who talked about how she could cope better on the days that she didn't have to go to the hospital. The days when she could, at least for a short period of time, live a normal life and do normal things. Of interest was the way that Emily described how she dipped in and out of normality, and used the metaphor of 'being put on a roundabout' to describe this feeling. The 'roundabout' was used to describe how periods of feeling good and accessing normality were often cut short by planned hospital appointments and procedures, which brought the reality of her illness back to the fore. She also spoke of the anger that she felt towards the dizzy turns that she was experiencing, which from all of the concurrent symptoms that she was experiencing at that time, she directly attributed as preventing her from accessing the little normality that she had left in her life:

Roma: ... last time you spoke about your dizzy turns and you were saying that you felt angry about it ...

Emily: Mm hmm...

Roma: If you don't mind could you just explain, why you described it in that way?

Emily: It was because that affects my life again. Because again, I've to try and find another way to get a way around it, from day to day, because the dizziness is keeping me back from the wee bit normality I've got. I've got tae, this is something else that's eh, coming into my life that I don't want it to be there. I just want it away out my life for good, no just for a couple of weeks, and so far I cannae get it to find out what's causing it, so I think that's why I'm angry, again, it's nobody's fault, just me I get browned off, maybe that's the word, and that's what makes me angry ... [pause] ... It's funny 'cause I'm, you just, I mean, I don't know, again, these things are only human I think, people that have, that have, live a normal life they get browned off as well if something goes wrong that's keeping them off their daily routine, you know what I mean, so, that's just something again that goes along wi' different things, only I think at time, I just get too many oh them, to get browned off with and that's why I get angry. That's all (Emily, interview 2, page 14).

The heightened anger that Emily felt towards her dizzy turns is evident, and this appeared to be due to this symptom in particular from all the rest she was experiencing preventing her from accessing the little periods of normality that she had left in her life. There is an underlying sense that she felt that if she could get rid of this disruptive symptom for good, then her periods of normality would last longer. However, she appeared to feel frustrated as she couldn't find out what was causing her symptom and therefore could not source ways in which to manage it. Throughout the excerpt is a sense that Emily felt that she was a victim of her illness and this may have been due to the feelings of low self esteem and worthlessness that she expressed at other times in her interviews. Linked to such negative perceptions of herself was the way that Emily tried to

salvage some positive images by implying that her reaction was to be expected and that anyone else in the same position would have acted in a similar way.

9.5 Conclusion

This chapter has demonstrated the core role that the experience of symptom clusters played in the loss of sense of self experienced by the participants as they prevented them from undertaking many of the roles/activities that they had been accustomed to in the past and in which they had built positive self images upon. For many of the participants, despite experiencing multiple symptoms at this time, symptoms such as fatigue and breathlessness appeared to be of significant salience to them due to their direct impact on their level of physical functioning. For some, their loss of sense of self was most profound at times when they experienced concurrent symptoms of high severity, which resulted in the participants no longer recognising themselves and viewing their body as something that was 'alien' and unfamiliar to them.

The findings have also demonstrated how being a burden closely followed on from the loss of sense of self experienced by the participants due to the symptom clusters that they were experiencing

and the heightened feelings of anger, guilt, frustration and distress which often accompanied this. The chapter has also illustrated the strategies employed by some of the participants to try and intentionally hide the multiple symptoms that they were experiencing from their loved ones, in an attempt to try and protect them from the burden of their illness.

The results presented in this chapter have also highlighted how the participants, when faced with a threat to the self, due to the symptom clusters that they were experiencing, mobilised resources to try and maintain a coherent and valued sense of self. This included using strategies such as downward comparison and striving for normality, the state of their life before being diagnosed with lung cancer.

With reference to this thesis and the study of symptom clusters in patients with advanced lung cancer, the results of this chapter have demonstrated that the experience of symptom clusters in patients with advanced lung cancer is not simply reflective of the physical manifestation of the symptom experience, but has far reaching consequences on an individual's life and sense of self. The results of this chapter have demonstrated how complex the experience of

symptom clusters in patients with advanced lung cancer is, impacting on the individual within the context of their life in a number of ways.

Such findings highlight the need for studies exploring the concept of symptom clusters in patients with cancer, not to ignore, but to recognise and address this complexity. Having presented the findings pertaining to the super-ordinate theme of 'Symptom clusters and loss of sense of self', the following chapter will follow on from this and discuss the findings of this study relative to the research questions asked and with reference to the wider literature and, in doing so, will make recommendations for future research and practice.

Chapter 10 Discussion

10.1 Introduction

This chapter discusses the findings of this study in relation to the research questions posed in this thesis and the wider literature. Based on the new information generated by this study, it will be postulated that the study of symptom clusters in patients with cancer, with its reductionist approach to measurement, needs to widen this approach, to one that encompasses the central elements of the patient experience of this phenomenon, and therefore recognises the influential roles that context and meaning play.

This discussion of the results presented in this thesis pertaining to the study of symptom clusters in patients with cancer, will be followed with recommendations being made for future research and clinical practice, before a conclusion to this thesis is made. However, prior to these findings being considered, it is important to discuss the strengths and limitations of this study. In line with the selected methodology (IPA), and akin to Chapter 1 (Introduction) and Chapter 4 (Methodology), the

strengths and limitations of this study will be discussed using the first person.

10.2 Strengths and limitations of this study

I feel that the main strength of this study is the homage that it pays to the role of the experiential expert – the patient, an integral element of the study of patients with cancer, who has largely been neglected in symptom cluster research to date.

I demonstrated this patient focus with the qualitative approach I employed in this study, which, in comparison to quantitative approaches, did not attempt to reduce the patient experience to objective data explained using statistical associations, but aimed instead to capture the patient experience of this phenomenon in all its reality and complexity. This patient focus was further strengthened by my selected methodology, IPA, with its idiographic focus and commitment to understanding the lived experience of the individual within the particular context of their life world (Smith et al. 2009a:29). My choice to use unstructured interviews as a method of data collection further added to this patient focus. As discussed in chapter 7, my choice to use

unstructured interviews was based on my review of the literature (see chapter 3) and my observation that the concept of symptom clusters within the discipline of cancer nursing and the associated definitions currently used had not been developed inductively and therefore, it may be argued, might represent the viewpoint of the researcher and not the patient. I therefore wanted to inductively elicit what the lived experience of symptom clusters in patients with advanced lung cancer was, and I felt that the only way to do this was to ensure that I did not introduce any predefined concepts, but to allow people who were experiencing symptom clusters to openly talk about issues that they felt were of salience to them within their lives. This unstructured approach in the exploration of cancer related symptoms that have been argued to be poorly defined, such as fatigue, for example, has been previously reported in the literature (Magnusson et al. 1999; Glaus et al. 1996).

In order to ensure that I explored the phenomena of symptom clusters using this unstructured approach, if at any time the patient mentioned any symptoms within their experiences, I always probed, asking them to elaborate in greater detail about their experiences, particularly at times when they experienced multiple symptoms, noting whether or not they perceived any of the characteristics of symptom clustering evident

within current definitions and the literature. Furthermore, in line with my selected methodology (IPA) with its focus on cognitions, when the participants talked about their symptoms, I asked them to tell me what they were thinking at that time, what was going through their minds, and how they felt, in order for me to comprehend how people with advanced lung cancer experiencing multiple, concurrent symptoms perceived their symptom experiences, and whether any commonalities existed between their perceptions of their multiple symptoms and what the current evidence base pertaining to the concept of symptom clusters in patients with cancer suggests.

It could be argued that using a more structured approach, directly asking the participants their perceptions of symptom clusters, may have provided more focused data relative to the experience of symptom clusters in patients with advanced lung cancer. However, I felt that asking patients to talk about their experiences of symptom clusters would have been problematic, as this term is not recognised within lay accounts, and asking people to directly talk about phenomena that they are not familiar with appeared to be inappropriate. Furthermore, if a more focused approach had been used, I felt that I ran the risk of losing the essence of the inductive approach that I intended to use with IPA by

introducing characteristics of a concept that had been predefined by researchers, and one that may have influenced the way that the respondents replied to the questions posed.

In line with this unstructured approach was also my choice to ask the question at the start of the first interview, 'what does cancer mean to you?' The decision to ask this question was made for a number of reasons. As discussed above, I could have asked the respondents a direct question about symptom clusters, but based on the inductive nature of my study, the lack of recognition within lay accounts as to what a symptom cluster is and the risk of influencing the respondents' responses, I chose not to take this line of questioning. In cognisance of the factors previously cited, and taking into consideration my epistemological stance and the methodology selected (IPA) (see chapter 4), I felt that it was appropriate to open the interview with a question which focused on meaning. This type of questioning, focusing on meaning, is common in studies employing IPA, based on its appreciation of the central role that cognitions play in the lived experience (Smith et al. 2009a) and has previously been used in studies exploring the symptom experience of patients with cancer (Magnusson et al. 1999). Furthermore, there is an abundance of literature that demonstrates the

core role that meaning plays in the illness experience (Thorne 1999; Johnson Taylor 1995; O'Connor et al. 1990; Kleinman 1988a; Good and Good 1980; Mishler 1979; Frankl 1959), and it's relevance to the symptom experience (Krishnasamy 2000; Ferrell and Dean 1995; Kleinman 1988a; Good and Good 1980). Moreover, I also felt that this approach took into consideration the viewpoints of seminal authors within the area cancer symptom research, who view symptoms as not being simply a '*reflection of the disease*', but as representing the meaning that the illness holds for the individual (Kirkmayer et al. 1994; Tishelman et al. 1991). This point is characterised in the following quote by Dan:

Dan: See if I could breathe, I'd be perfect within myself – perfect (Dan, interview 2, page 52).

Relative to the study sample, limitations include the high rate of attrition, with three patients dying before the second interview could be conducted. It therefore may be questioned whether having reduced the time between interviews may have prevented such levels of attrition. However, as previously stated, I felt that this issue was common in conducting research in people with advanced cancer (Harris et al. 2008)

and therefore, changing the timing of interviews would not prevent this level of attrition and may, in fact, have resulted in the overburdening of the frail patient population selected. Furthermore, it has to be acknowledged that all the participants in this study did have advanced lung cancer, and therefore it may be argued that patients with less advanced disease may have provided a different perspective of the experience of symptom clusters within their lives.

With regard to the study sample, the number of patients recruited to this study, whilst being the upper limit advocated for studies employing IPA (Smith et al. 2009a), is small, and therefore limits any generalisation of the findings to a wider patient population. Furthermore, the participants in this study were only recruited from one clinical site in Scotland, and this may further limit any generalisations made. Whilst it is openly acknowledged within the literature and in this thesis that the results of an IPA study '*represent a perspective rather than a population*' (Smith et al. 2009a:49) and that the findings are therefore held to be local to the patient population recruited, it may be argued that the high level of consensus between the participants in this study and transferability of the study findings to the wider theoretical and empirical literature (see section 10.3 that follows), provides

evidence to substantiate these tentative findings, and warrant their further exploration in a wider patient population.

A further consideration is that a more comprehensive understanding of the experience of symptom clusters in patients with advanced lung cancer may have been achieved if a mixed methods approach had been used (Burke, Johnston and Onwuegbuzie 2004). It is contended that this combination of both qualitative and quantitative approaches within a study allows the strengths and weaknesses of each component to be 'offset' to draw on the overall strength of the study (Bryman 2006). Furthermore, the different approaches used can be argued to have the ability to answer different research questions providing a more comprehensive understanding of the phenomena under investigation and provide the means of recruiting a wider sample of patients in which to draw conclusions from (Bryman 2006).

However, it has been highlighted within the literature that using mixed methods within a study is not merely a case of joining quantitative and qualitative approaches, and a number of researchers have highlighted the challenges in the adoption of this approach (Pope and Mays 1995).

Furthermore, there remains debate in the literature as to whether both methodologies can be successfully integrated. A recent literature review of mixed methods papers found that the majority of those papers reported qualitative and quantitative results independently of one another (O'Cathain et al. 2008). Moreover, a number of researchers have noted the challenges of combining qualitative and quantitative approaches due to the differing epistemological and ontological perspectives inherent to each (Bryman 2007; Wendler 2001).

However, whilst acknowledging the potential utility of using a mixed methods approach in this study, I contend that taking into account my aim, to inductively explore and understand the experience of symptom clusters in patients with advanced lung cancer, using qualitative and quantitative methods in an investigation such as this, might have limited the depth of data collected (Driscoll et al. 2007). Furthermore, it has been postulated by Krishnasamay (2000) that *'Without securing meaning before measurement, it is unlikely that an instrument will provide data which can contribute to an understanding of how the phenomena under investigation impact on the lives of the participants and what factors exacerbate or relieve it'* (Krishnasamy 2000:411). Therefore, taking into account that lived experience of symptom clusters

has not previously been explored, and therefore the meanings that such experiences hold for the person experiencing this phenomena have not previously been elucidated, I felt that it was inappropriate to use an approach that would attempt to measure a phenomenon that is poorly defined and one that has not previously been explored from a patient experience perspective. Therefore, taking these factors into account, I felt that a qualitative methodology was the most appropriate approach to capture in depth the lived experience of symptom clusters in patients with advanced lung cancer and thus address the aims and research questions posed for this study.

It may also be contended that other qualitative approaches, instead of IPA, may have been more appropriate to explore the lived experience of symptom clusters in patients with advanced lung cancer. As discussed in chapter 4, based on my epistemological beliefs (contextual constructionist), a number of methodological approaches were considered in light of the aim of my study and the research question posed. These included Social Constructionist version of Grounded Theory, Discourse Analysis and IPA (Willig, 2001).

Whilst the Social constructionist version of Grounded Theory was an 'attractive' methodology to explore the lived experience of symptom clusters in patients with advanced lung cancer, it was not selected as this methodology was primarily developed to theorize social processes and to answer sociologically derived questions (Charmaz 2000). Furthermore, its suitability to answer research questions regarding the meaning and nature of the lived experience has been questioned (Willig, 2001) with some advocating the use of phenomenological types of inquiry for this. Discourse analysis was another methodology which may have been appropriate for use in this study. Whilst this approach offers a sophisticated understanding of the use of language, I felt that its sole focus on language and its dismissal of the role of cognitions, limited its ability to address the aim and research questions posed in this study. In order to explore and understand the lived experience of symptom clusters in patients with advanced lung cancer, I felt that it was important not only to focus how people talk about a phenomenon, but also to understand what they think about it and why. Therefore, I felt that it was important that the role of cognitions had to be central to any methodology that I adopted for use in my study and I felt that Discourse Analysis did not encompass this.

IPA, as opposed to the other methodologies which are consistent with a contextual constructionist approach, was selected for this study based on its phenomenological origins and focus on the lived experience of the person in the context of their own life. Furthermore, IPA highlights and pays homage to the role of cognitions within the lived experience, deeming this to be central to understanding how people understand and make sense of their experiences. Based on these two central components of IPA, I felt that this methodology was the most appropriate to address the aim of this study which was to explore and understand the experience of symptom clusters in patients with advanced lung cancer. Furthermore, this methodology had not previously been used in studies of symptom clusters in patients with lung cancer, and therefore had the potential to elicit new insights into the phenomena being explored.

Relative to the method of data collection selected and the sensitivity of the research topic as described in chapter 6, some of the participants did become tearful during their interviews. This commonly occurred when they talked about the losses that they had experienced since being diagnosed with lung cancer. At such times, the participants were given the opportunity to end the interview, but all declined. However,

after such events, in order to prevent any further upset, I did feel wary of probing any sensitive issues that were raised in fear of causing the participant any further upset, and this may in turn have limited the data collected and therefore the research findings to some extent.

Another potential limitation of this study was that although most of the participants were interviewed alone, two of the participants asked if their partners could sit in on the interview, which I felt that I had to allow on ethical grounds. This led to me having to address the impact that this might have on the data collected and its subsequent analysis. From the related literature, issues such as intrusion, inclusion, power and differences in opinion had been reported in joint interviews (Morris 2001; Askey 1996). However, Morris (2001), reporting on her experiences of using joint interviews in the cancer context, found that it did not appear to inhibit participants when discussing sensitive topics, at times provided a fuller account of their experiences, and was acceptable to them. A similar experience was found in this study during the interviews, that the presence of the partner did not appear to inhibit the interview process and, in line with Morris (2001), appeared to enhance the interview process.

Relative to the interviews conducted with the participants in this study, the temporal nature of the interviews needs to be considered in light of the phenomena under investigation and the advanced nature of the participants' disease. Whilst interviews are regarded by most as being the '*staple means of data collection within most kinds of qualitative research*' (Flowers 2008), the timeframe of the recall period is difficult to determine, and, as stated by Flowers (2008: 24-25), '*our "recall period" is often a complex sense of the past as seen through the lens of the present (the interview itself) and often tied to particular, salient experiences*'. Therefore, it may be argued that whilst the participants in this study were experiencing symptom clusters on recruitment to this study and did talk about their experiences of multiple concurrent symptoms during their interviews, some of their experiences elicited during their interviews, may pertain to their past experiences of lung cancer and therefore not at times when they were experiencing symptom clusters. Therefore, it must be acknowledged that some of the symptom experiences reported in this thesis may pertain to the symptom experience per se, and not directly to the concept of a symptom cluster. However, it may be contended that this limitation may also apply to previous qualitative studies of symptom clusters in patients with cancer reported in the literature (Lopez et al. 2011; Molassiotis et al. 2010; Molassiotis et al. 2008) and, to a certain extent,

studies that have employed quantitative methods of measurement, which, whilst often stipulating the period of recall, e.g last week or month, provide no means to glean as to whether the people filling in the questionnaires were experiencing these symptoms all at the same time or separately.

Furthermore, the approach adopted in this study raises the question as to what extent the data reflects the experience of symptom clusters or the symptom experience per se. Given the results, I feel that this thesis does reflect the lived experience of symptom clusters in patients with advanced lung cancer for the following reasons. Firstly, all the patients in this study were experiencing multiple, concurrent symptoms, and were therefore exhibiting the phenomenon which was the focus on this study. Secondly, I feel that the use of IPA and an unstructured approach to data collection, did allow me to explore the concept of symptom clusters in patients with advanced lung cancer, but in novel way. IPA facilitated an inductive bottom-up generation of data, allowing the participants to talk about issues of importance to them in their lives in the first instance, prior to me probing and exploring their experiences of symptom clusters. It may be argued that this approach facilitated an appreciation and understanding of the context in which the experience

of symptom clusters occurs, which, to date, has not previously been reported in the literature. Thirdly, in line with my IPA stance and my unstructured approach to data collection, is also cognisance of the fact that at times when the participants in this study (who were experiencing multiple, concurrent symptoms), talked about their symptom experiences, I did actively probe, trying to find out what they thought about their symptoms and why they thought that way. I feel that my observation that the participants in this study, not only chose to talk about their experiences of multiple symptoms, but also chose to focus their narratives on individual symptoms, does not imply that their narratives were not related to symptom clusters, but rather provide data, whilst tentative, to illustrate that people with advanced lung cancer, within the lived experience of symptom clusters, do not only focus only groups of symptoms, but also appear to pick out salient symptoms from the rest that they are experiencing at that time. Therefore, such findings do provide novel avenues of inquiry for future research in the area of symptom cluster to either support or refute the findings presented in this thesis.

Lastly, it must be acknowledged that the transcripts and the quotes that are written in this thesis are written in local dialect, and therefore this may make it more difficult for some readers to understand.

Having discussed the strengths and limitations of this study, the following section will focus on the study findings with reference to the research questions posed and the wider literature.

10.3 Discussion of study findings with wider reference to the wider literature

The previous section has discussed the strengths and limitations of this study, where it has been argued that the main strength of this study is the homage that it pays to the experiential expert – the patient. This final section follows on from this patient-centred focus, where it is discussed how the findings of this study have replied to the two research questions posed, which are:

- What is the 'lived experience' of symptom clusters in patients with advanced lung cancer?
- How do people with advanced lung cancer understand and make sense of the symptom clusters that they are experiencing?

Based on the findings presented in this thesis, it will be argued that the study of symptom clusters in patients with cancer, with its affinity to the biomedical model, is significantly limited as it does not encompass the core roles that context and meaning play in the lived experience of this phenomenon. It will therefore be contended that it is imperative that the study of symptom clusters in patients with cancer widens its approach and starts to acknowledge these important elements of the lived experience. Only by doing this can we ensure that future research fully reflects the real life manifestations of the experience of symptom cluster in patients with cancer, which, it can be argued, is the only basis from which effective, patient-centred, symptom cluster interventions can be developed.

This section will start by providing a summary of the key findings of this study, detailing for the first time in the literature, the lived experience of symptom clusters from the perspective of patients with advanced lung cancer. This will then be followed with a discussion of the results of this study with reference to the research questions and wider literature, particularly their importance and relevance to existing research that has been conducted in the area of symptom clusters in patients with cancer to date. This summary will then be followed by

recommendations for future research and practice, before conclusions from this thesis are drawn.

10.3.1 Summary of key findings

In reply to the first research question asked in this thesis, it is clear from the findings of this study that the lived experience of symptom clusters in patients with advanced lung cancer manifests itself in a fear of death, 'felt stigma', loss of sense of self and feelings of being a burden, which cause significant distress and suffering within the individual in the context of their lives.

From the results of this study, what is also apparent is that within the lived experience of symptom clusters in patients with advanced lung cancer, four core symptoms (fatigue, cough, pain and breathlessness) commonly comprise the symptom clusters experienced and that the occurrence of symptom clusters are most prevalent during periods of cancer related treatment. Furthermore, within the lived experience of symptom clusters in patients with cancer, most of the clusters experienced, particularly during periods of treatment which are transient in nature, with others remaining throughout the patient journey.

Based on the findings of this study and of particular significance to this thesis, is the notion of the sentinel symptom within the lived experience of symptom clusters in patients with advanced lung cancer, with patients not perceiving all the concurrent symptoms that they experience as being of equal weighting, but instead giving some symptoms priority over others based on the meanings that they ascribe to them.

In reply to the second research question posed in this thesis, it is evident that people with advanced lung cancer understand and make sense of the symptom clusters that they are experiencing in a number of ways. For some of the participants in this study, they tried to understand and make sense of the symptom clusters that they were experiencing by using the concurrence as a means of attempting to deduce the cause of one symptom based on the occurrence of others.

Another way that the participants in this study understood and made sense of their symptom clusters was by using the meanings that they ascribed to their experiences of this phenomenon. In this study, the participants commonly associated their experiences of symptom clusters

with a fear of death, feelings of felt stigma and a loss of sense of self. Furthermore, what was apparent was that these meanings that the participants ascribed to their experiences of symptom clusters were in turn, derived from the wider context of their lung cancer diagnosis, and the way that they associated their illness with impending death and feelings of stigma. These meanings also influenced the participants' interpretation of symptom clusters, in the way that they appeared to pick out salient symptoms from all the rest that they were experiencing at that time based on the symbolic connotations that specific symptoms held for them.

10.3.2 Study findings with reference to the wider literature

The previous summary and the results chapters in this thesis have provided for the first time, an insight into the lived experience of symptom clusters in patients with advanced lung cancer, illuminating its complexity, and the core role that context and meaning play in such experience. However, on comparing the findings of this study with the evidence base pertaining to the study of symptom clusters in patients with cancer, what is apparent at the most basic level is the evident disparity observed between what the patients' actual experiences of symptom clusters and the experience that the data in the current body

of evidence depicts. This contrasting observation, relative to the results of this study, applies to both the current definitions offered in the literature and empirical evidence to date and will be discussed in relation to the literature in the section that follows.

10.3.3 The patient experience and current definitions

When we look at current definitions of symptom clusters detailed below, it is clear from the results of this study, that the core elements of the patient experience of this phenomenon are not recognised.

When three or more concurrent symptoms are related to each other they are called a symptom cluster. The symptoms within a cluster are not required to share the same etiology (Dodd et al., 2001b).

Later added to the definition -

Symptom clusters may have an adverse effect on patient outcomes and may have a synergistic effect as a predictor of patient morbidity (Dodd et al, 2004).

When two or more symptoms that are related to each other and that occur together. Symptoms clusters as composed of stable groups of symptoms, are relatively independent of other clusters, and may reveal specific underlying dimensions of symptoms. Relationships among symptoms within a cluster should be stronger than the relationship among symptoms across different clusters. Symptoms in a cluster may or may not share the same etiology (Kim et al. 2005).

For example, Dodd's (2001b; 2004) definitions focus on the number of symptoms within a cluster, the relationship between cluster symptoms, their aetiology and impact on patient outcomes. Kim's (2005) definition covers the same biomedical domains except she extends details on the relationships between different clusters of symptoms.

However, when referred back to the findings of this study in chapters 8 and 9 detailing the patient experience of symptom clusters, the inherent limitations of these current definitions become apparent. Whilst there are some similarities between the lived experience of this phenomenon and current definitions, such as the way that the participants in this study did appear to associate the occurrence of certain symptoms with others, the findings of this study, nevertheless do demonstrate how limited current definitions are. This is particularly evident in the way that the current definitions lack any detail of the subjectivity of the experience of symptom clusters, the distress associated with such experiences and more importantly do not address the central role that context and meaning play. This point is exemplified in the following quotes by Flora when she talks about the multiple concurrent symptoms she experienced during her radiotherapy treatment:

Flora: Weak, I could hardly do anything, it took me all my time, it gave you a very tired feeling, it took you all your time to get out of bed and put your clothes on, sometimes I just put my dressing gown on, and come down, I still had my nightie on, you know that's how weak it felt, you know. But after a week I started to get better again, mm hmm. But I really felt ill for a week, I did ...Tired, tired, as if I'd been ill, you know, say you had a bad illness, say like a chest infection or anything like that and you feel weak, I had one not so long ago didn't I? I had a chest infection and pleurisy, mm hmm ... I was just dragging my feet behind me, I was ... that's when I let [daughter] make my dinner and that, you know make my food and I was kinda off my food as well, mmm mmm, ... Flora, interview 1, page 24).

Such experiences are further elaborated in the quote that follows, when Flora talks about her thoughts during this time:

Flora: All I could think was my gosh, I hope I get better, uh huh, this is a terrible feeling, uh huh. Why did I feel it was like that? Well I'd never ever felt like that before, you know I'd never felt like that before because I was always fairly healthy and got around, but it was horrible, mmm mmm. But I used to say to myself "I must get better, I will get better", and I did get better ...

Roma: Could, if, you know, if you want, can you tell me a wee bit more about that, about why you were thinking that at the time – I must get better, I will ... ?

Flora: Well, I had lots of things I wanted to do, you know ... yes, that's how I felt, there was lots of things I wanted to do, mm hmm. I can't go just now [meaning to die], there's tons of things I want to do, mm hmm ... [slight pause] ... (Flora, interview 1, pages 25-26).

The findings of this study therefore raise questions as to why current definitions have chosen to neglect these crucial elements of the lived experience of symptom clusters in patients with cancer.

It may be argued that the neglect of these core elements of the lived experience of symptom clusters in patients with cancer has occurred because current definitions have not been developed inductively, using patient experience to guide them. It may therefore be contended that current definitions represent the viewpoint of the researcher and not the patient. Thus it may be argued that these definitions are hegemonic and that their neglect of the patient perspective and predominant biomedical focus has significantly contributed to the development of a body of empirical evidence which portrays a narrow view point of the reality of the lived experience of symptom clusters within a person's life.

The neglect of these important, subjective characteristics of the experience of symptom clusters revealed by this study, is, to an extent, surprising, considering they are recognised by the theories (Lenz and Pugh 2008; Humphreys et al. 2008) and model (Armstrong 2003) which claim to underpin this body of research. Whilst the results of this study

are novel in that they have not previously been reported relative to the experience of symptom clusters in patients with advanced lung cancer, of interest and significance to this thesis is that all of these conceptual frameworks claiming to underpin the study of symptom clusters in patients with cancer are reflected to some degree in the findings of this study.

For example, the Theory of Unpleasant Symptoms (Lenz et al. 1997) focuses on the antecedents (context) of the symptom experience and does not only focus on the intensity and timing of symptoms but also acknowledges the distress associated with the symptom experience and the quality, that is to say what it feels like to have a symptom. Within the Theory of Symptom Management (Humphreys et al. 2008) commonalities with the findings of this study include the way that it focuses not only on the experience of the symptom but also its perception, and the way that it pays homage to the importance of the role of context in the symptom experience. The Model of Symptoms Experience developed by Armstrong (2003) which also claims to accommodate the concept of symptom clusters, has much in common with the participants' experiences of symptom clusters in this study, particularly the role that it affords to meaning in the symptom cluster

experience. Within this model there are two types of meaning: 'situational' meaning, which is defined as being the person's 'perception of a new event and their capacity to handle it', and existential meaning which is their 'global representations of their places in the world' (Armstrong 2003:603). Of relevance to the findings of this study is the way that this framework portrays 'existential meaning' as encompassing the 'situational meaning' of the symptom, which, in turn, surrounds the experience of symptoms. This conceptualisation fits well with what was observed in this study relative to the experience of symptom clusters, as it was the meanings that the participants ascribed to their lung cancer diagnosis, which in turn, influenced the meanings that the participants ascribed to their experience of symptom clusters, which in turn manifests itself in the actual way that symptom clusters were understood and made sense of by the participants.

Therefore, it may be argued that the similarities observed between the findings of this study and the conceptual frameworks that claim to underpin this body of research (Lenz and Pugh 2008; Humphreys et al. 2008; Armstrong 2003) suggest that researchers developing current definitions of symptom clusters have either neglected to consult the theoretical base which informs it or have instead used a biomedical

framework, choosing to pick objective parameters that are easily measured and quantified. In either case, it may be contended that it has been the researcher who has defined what the core characteristics of symptom clustering are, such as the number of symptoms in a cluster and the relationships between symptoms, which, when compared to the results of this study, can be argued to represent little of the patient interpretation of this phenomenon.

Therefore, such observations call for current definitions of symptom clusters in patients with cancer, to widen their focus, acknowledging the subjectivity of the experience of symptom clusters, the distress that such experiences can cause, and crucially, the core role that context and meaning plays in such experiences.

This argument for current definitions of symptom clusters to broaden their focus, is supported not only from the new insights of the lived experience of symptom clusters gleaned in this study, but is also substantiated by the wider literature exploring the patient experience of symptoms in the area of chronic illness (Thorne 1999; Devins 1994; Charmaz 1991; Bury 1991; Corbin and Strauss 1987; Charmaz 1983;

Bury 1982) and cancer (Bender et al. 2008b; Desnoo and Faithfull 2006; Ekfors and Petersson 2004; Booth et al. 2003; Murray et al. 2002). These studies, akin to the results detailed in this thesis, have reported how patients with such conditions do not focus on objectifying their symptoms, but have a greater concern for the subjective manifestations of their symptoms. For example, the seminal works of scholars such as Kleinman (1988a; 1988b; 1980), Cassell (1982; 1978), Charmaz (1991; 1983) and Bury (2001; 1997; 1982) have all illustrated in some way the negative impact of the symptom experience on the self and how this impacts on those around them. Similar findings have also been recently reported in patients with cancer (Cayless et al. 2010; Hubbard et al. 2010; McCann et al. 2010) where it has been argued that many commonalities exist between the cancer experience and the experience of chronic illness.

Many studies have also reported the central role that meaning plays in the symptom experience. For example, the fear of death experienced by the participants in this study has also been reported previously in the literature, relative to the experience of pain, breathlessness, weight loss and fatigue (Lindqvist et al. 2006; Hopkinson et al. 2006; Lindqvist et al. 2004; Alderbratt and Stang 2000; O'Driscoll et al. 1999; Ferrell and

Dean 1995). Of particular relevance and reflective of the findings of this thesis is a study by Aldelbratt and Strang (2000) in patients with brain tumours, who reported that 'worrying' symptoms, such as headaches, acted as 'trigger phenomenon' that were regarded by patients as being '*memento mori*' of their impending mortality, causing significant anxiety and distress. As with fear of death, perceived stigma has also been reported relative to the symptom experience in patients with cancer (Wilson and Luker 2006; Chapple et al. 2004; Rosman 2004; MacDonald and Anderson 1983) and, as was found in the patients in this study, such experiences often centralised around a fear of potential discrediting and the overt visibility of symptoms that were symbolic of cancer, such as breathlessness.

Therefore, the importance of these wider subjective experiences of symptom clusters, particularly the role of context and meaning, cannot be ignored based on the findings of this study, and the studies detailed above. Furthermore, this argument for current definitions of symptom clusters in patients with cancer to address the context and wider, subjective manifestations of the symptom experience, is also supported in alternative models of care (Crossley 2000; Good and Good 1980; Engel 1977). These models of care appreciate and include these wider

subjective domains (see chapter 2), and, as argued earlier in this thesis, appear to be more fitting to accommodate and appreciate the complexity and subjectivity of the illness experience from the perspective of the patient.

10.3.4 The patient experience and current empirical base

The lack of semblance with the body of evidence on symptom clusters in patients with cancer and the findings of this study also extends to the results of empirical studies, which, it can be argued, do not recognise these crucial elements of the patient experience of this phenomenon, as depicted by the participants in this study.

Whilst there is consensus between the results of this study and current empirical base, regarding the existence of core symptoms (fatigue, breathlessness, cough and pain) that commonly constitute symptom clusters identified in patients with cancer (Molassiotis et al. 2010; Reyes-Gibby et al. 2006; Beck et al. 2005; Fleishman 2004; Niven 2003), the high prevalence of symptom clusters during periods of cancer related treatment (Lopez et al. 2011; Kim et al. 2009; Kim et al. 2008; Maliski et al. 2008; Honea et al. 2007) and the nature of

symptom clusters with some being transient and others chronic in nature (Molassiotis et al. 2010; Gift et al. 2003). A significant limitation of this body of evidence is that it does not acknowledge the core roles that context and meaning play in the experience of this phenomenon. It may be argued that the neglect of these important domains of the lived experience of symptom clusters in patients with cancer has occurred due to the predominant use of reductionist methods of measurement, which, due to their narrow view point, have simplified a phenomenon which is by its nature complex, and deeply embedded in context and meaning.

Therefore, the critique of the biomedical model offered in chapter three of this thesis also extends to the study of symptom clusters in patients with cancer, where it can be argued that the dominance of reductionist methods has excluded many of the human aspects of the experience of symptom clusters (Thorne 1999; Cassell 1982; Cassell 1978; Engel 1977), have not comprehended the whole person (Cassell 1982), have not captured the full reality of the experience of symptom clusters, and have not acknowledged the social, historical and cultural factors that influence such experiences (Willig 2001). These findings also support the critique offered by Krishnasamy (2000) that the use of reductionist

methods of measurement have little relevance to the lives of the individual and that they often hide the distressing facets of the symptom experience. This notion is supported by Benner who states that the limitations of reductionist methods of measurement are most apparent relative to the symptom experience (Benner and Wrubel 1989).

The critique of the limitations of the predominant use of reductionist methods of measurement in the study of symptom clusters in patients with cancer to date can also be contended on the grounds that such methods should not be used to measure phenomena that are poorly understood and defined (Krishnasamy 2000). The results of this study have significantly contributed to this argument, highlighting the limitations of current definitions of symptom clusters in patients with cancer and how they have limited semblance with the lived patient experience of this phenomenon within a person's life.

Of relevance to and supporting this discussion is that such limitations in current definitions have also been previously identified in the literature, where repeated calls for the clarification of the concept of symptom

clusters in patients with cancer have been made (Hadi et al. 2008b; Miaskowski and Aouizerat 2007; Barsevick 2007b; Kim et al. 2005; Dodd et al. 2004). This is articulated by Dodd (2004), who states that the study of symptom clusters in patients with cancer is in the phases of concept exploration and clarification, where the concept has been introduced in the literature but *'it is too early to articulate its definite properties and potential explanatory power'* and where the refining of symptom clusters as a concept is required in order to *'resolve the conflicts about meaning and definitions'* (Dodd et al. 2004:77). Findings of this study further support this observation, highlighting how current definitions do not address the core elements of the lived experience of this phenomenon and therefore raise the question why researchers are trying to measure a concept which is not clearly articulated and where core characteristics have not been meaningfully defined.

This viewpoint is shared by Krishnasamy (2000), who states that by trying to measure poorly defined phenomena using reductionist methods, without clarification of the meanings that the phenomena holds for patients in the context of their lives, we are unlikely to *'contribute to an understanding of how the phenomena under*

investigation impacts on the lives of patients and what factors exacerbate or relieve it' (Krishnasamy 2000:411).

Once again, this observation, relative to the findings of this study, highlights a discrepancy in the framework of this body of research and calls for more studies of the patient experience of symptom clusters in order to determine what the core characteristics of symptom clusters in patients with cancer are, to further clarify the concept, to thereafter dictate what domains of this experience are meaningful to the patient, and, ultimately, which characteristics are amenable to measurement.

Linked to this discussion is how this study has demonstrated the importance of addressing the experience of symptom clusters at the level of the individual within the context of their life. It can be argued that reductionist methods of measurement aim to make generalisations at a group level. However, within this study, whilst commonalities did exist between the participants' experiences of symptom clusters, what was also apparent was the idiographic nature of their experiences of this phenomenon, with particular relevance to the way that they would choose to pick out 'salient symptoms' from the clusters of symptoms

that they were experiencing. This highlighting of individual symptoms within the experience of symptom clusters, varied from individual to individual, based on the meanings that they ascribed to these specific symptoms. For example, sentinel symptoms which were singled out by the participants based on their symbolic connotations with perceived stigma, all differed from each other, and included rash, breathlessness, cough and hair loss. Therefore, such observations, whilst highlighting the limitations of reductionist approaches, and the need to further explore the experience of symptom clusters at the level of the individual, may also open up novel avenues of thought for the development of patient-centred symptom cluster interventions. It may be postulated that if we target the symptoms that patients prioritise and highlight as being meaningful in their lives, then it is possible that effective treatment of these 'sentinel' symptoms will have a beneficial crossover effect on the other cluster symptoms being experienced.

Of note is that this prioritisation of symptoms has been previously reported in patients with cancer with symptoms such as fatigue, pain and dyspnoea being commonly identified (Butt et al. 2008; Stromgren et al. 2006; Tishelman et al. 2000). However, such studies have also demonstrated that the symptoms of greatest intensity are not

necessarily the ones that are prioritised by patients (Butt et al. 2008; Tishelman et al. 2000).

This singling out of 'sentinel' symptoms within the experience of symptom clusters in patients with cancer, therefore, emphasises the importance of targeting and prioritising the treatment of symptom clusters, not only based on objective measures such as intensity, but also on the importance of capturing the meaning of symptoms in order to understand the impact and nature of these symptoms in the person's life. This hierarchical positioning of the importance and meaning of symptoms by patients with cancer experiencing symptom clusters can therefore inform how the research framework for this phenomenon may be modelled and further developed.

Of relevance to this discussion is also the suggestion previously made in the literature (Lopez et al. 2011; Molassiotis et al. 2008) that the patient narrative may be a better tool than the use of reductionist methods of measurement and statistical tests in order to determine evidence of symptom clustering in patients with cancer. The findings of this study support such calls because an appreciation of lay accounts

allows understanding to develop, not only regarding what symptoms are of greatest salience to the person, but also of what potential interventions may be of use. The notion of a 'sentinel' symptom as a potential symptom cluster intervention as discussed above, provides insights into the value of lay accounts (Bury 2001) and how they may be used to inform the development of future interventions.

This study and the novel insights which it provides on the lived experience of symptom clusters in patients with advanced lung cancer and, as substantiated by findings in the wider literature, therefore provides evidence to suggest that current definitions offered in the literature and the empirical base representing the study of symptom clusters in patients with cancer are limited as they do not encompass core elements of the lived experience of this phenomenon as depicted in this study, such as the role of context and meaning. It may be argued that such significant limitations have transpired due to the biomedical framework adopted in the study of symptom clusters in patients with cancer to date, with its focus on the objective domains of the symptom experience and use of reductionist methods of measurement. Findings from this study suggest that such an approach does not encompass the full perspectives of the patient. Therefore it may be postulated that by

continuing to conduct research on the concept of symptom clusters in patients with cancer using a predominantly reductionist approach, risks future studies being conducted which are of limited relevance to the patient and to the people caring for them and therefore are of limited value in developing future interventions.

Therefore, the findings of this study and the new contributions made to this body of research by exploring the lived experience of this phenomenon, may allow researchers to address current limitations and offer new directions for the study of symptom clusters in patients with cancer, taking cognisance of the patient perspective. Such an approach would ensure that those with the experiential knowledge can contribute to the determination of what the core characteristics of symptom clusters in patients with cancer are and therefore strengthen the scientific base which underpins this important and emerging body of research.

Therefore, having discussed the novel contributions and implications of the findings of this study to the existing body of research on symptom clusters in patients with advanced lung cancer, the following section will

conclude this thesis and make recommendations based on findings of this study for future research and practice.

10.4 Conclusions and Recommendations

In conclusion, this study used a qualitative approach, (informed by a contextual constructionist epistemological stance), utilising IPA to explore the lived experience of symptom clusters in patients with advanced lung cancer and identified how patients understood and made sense of the experience of this phenomenon. This IPA approach was original to the exploration of the lived experience of symptom clusters in patients with advanced lung cancer and has not been reported previously in the literature. The benefits of the use of IPA and unstructured interviews demonstrated the strengths of this patient-centred approach by the richness and depth of the data collected, and, in particular, its ability capture the context and the meaning embedded in the experience of symptom clusters in patients with advanced lung cancer.

The findings of this study provide new insights into the lived experience of symptom clusters in patients with advanced lung cancer by exploring

the experience of this phenomenon from the perspective of the patient. The results of this study demonstrated that the lived experience of symptom clusters in patients with advanced lung cancer does not manifest itself within the confines of the biomedical model as the current body of evidence would lead us to believe, but has far reaching consequences for the individual in the context of their life. For the participants in this study, that is, patients with advanced lung cancer, the experience of symptom clusters manifests itself in a fear of death, 'felt' stigma, loss of sense of self and feelings of being a burden.

The findings also provide new insights into how patients with advanced lung cancer understand and make sense of their experiences of symptom clusters. For some, the concurrence of symptoms within a cluster acted as a means of them trying to deduce the cause of the symptoms that they were experiencing, with them often attributing the occurrence of one or two symptoms on the formation of another.

Another way that the participants in this study understood and made sense of the symptom clusters that they were experiencing was by using the meanings that they ascribed to concurrent symptoms that

they were experiencing. In this study, the participants frequently associated their experiences of symptom clusters with a fear of death, feelings of stigma, and a loss of sense of self. Furthermore, what was apparent from the findings of this study was that the meanings that the participants ascribed to their experiences of symptom clusters were derived from the wider context of their lung cancer diagnosis, and the way that they associated their illness with impending death, feelings of stigma and a loss of sense of self.

These meanings that the participants ascribed to their experiences of symptom clusters also appeared to result in them choosing to pick out salient symptoms from all the rest that they were experiencing at that time, due to the strong symbolic connotations that these individual symptoms held for the participants. These results therefore indicate that patients with advanced lung cancer do not view all of their symptoms as being of equal weighting but instead give certain symptoms greater priority than others based on their meaning within their lives; these might be defined as 'sentinel symptoms'. Such findings therefore provide unique insights into the study of symptom clusters in patients with advanced lung cancer.

The findings have also contributed to the evidence base by providing evidence to substantiate the need to broaden the quantitative approach which has dominated the study of symptom clusters to date, with its focus on objective parameters that can be only be quantified and assessed using statistical associations. The lack of semblance with the current definitions and empirical evidence and the findings of this study, suggest that current definitions are limited and that reductionist methods of measurement are oversimplifying a phenomenon which, by its very nature, is complex. By placing these definitions and methods of measurement as boundaries within the research framework, it may be argued that it is preventing the generation of data which can open up new avenues of inquiry and the subsequent development of patient-centred symptom cluster interventions.

Based on the results of this study, it is argued that in order to strengthen the scientific and empirical base underpinning the study of symptom clusters in patients with cancer, there is a need to widen its scope, to encompass the perspective of the patient. This has the potential to facilitate the identification of what the core elements of the experience of symptom clusters in patients with cancer are. This, in turn, can then be used to redefine definitions to reflect the real life

experiences and perspectives of the patient, and not the researcher. By doing this we are also more likely to be measuring what is meaningful to the patient. It is upon this basis that effective symptom management interventions can be developed, that will make a significant impact on the lives of the individual and within clinical practice. Therefore, based on this discussion of the results of this study, the following recommendations for future research and clinical practice are made.

10.5 Recommendations for research

The new insights offered by this research have many implications for the study of symptom clusters in patients with advanced lung cancer. First, they provide evidence to substantiate the limitations of reductionist methods of measurement, which have significantly influenced the study of symptom clusters to date. Such limitations are demonstrated by the way that current definitions and the existing empirical base do not acknowledge the core role that context and meaning play in the lived experience of symptom clusters in patients with advanced lung cancer. Therefore, this thesis advocates that research exploring the experience of symptom clusters in patients with cancer widens its scope and moves away from its reliance on

reductionist methods of measurement, encompassing an appreciation of the contributions that the patient experience of phenomenon can make to this emerging body of research, and one that instead of trying to simplify such experiences, addresses them in all their complexity.

Secondly, linked to this recommendation is a call for the re-conceptualisation of current definitions of symptom clusters in patients with cancer, which, it can be argued, based on the findings of this study, represent a narrow viewpoint of the reality of the experience of this phenomenon within a person's life. In order to ensure that current definitions are grounded in 'reality', it is imperative that more qualitative studies like this one are conducted, exploring the lived experience of this phenomenon in all its complexity. Generating further such data will allow the research community to gain consensus of the core characteristics of symptom clusters in patients with cancer in order to direct future research which is more meaningful and, ultimately, will strengthen the current evidence base.

Thirdly, the findings also highlight the need for further research to explore the role of context and meaning in the experience of symptom

clusters in patients with cancer and its future place in revised conceptualisations. Based on the findings of this study, the depth of data collected and the novel insights provided, it may be argued that qualitative methodologies, informed by a contextual constructionist stance such as IPA, are well placed for such exploration, allowing the experience of symptom clusters in patients with advanced lung cancer to be fully elucidated. Furthermore, the notion of a 'sentinel symptom' as discussed previously, warrants further consideration, as this may open up new and innovative avenues for the development of meaning-based symptom cluster interventions in the future.

10.6 Recommendations for clinical practice

The results of this study have implications for practitioners involved in the assessment and management of symptom clusters in patients with cancer. The findings have highlighted the importance of recognising the complexity of the experience of symptom clusters in patients with advanced lung cancer, and the core roles that context and meaning play in such experiences. Therefore, such findings call for clinicians involved in the assessment and management of symptom clusters in patients with cancer, not to rely on reductionist methods of measurement which aim to simplify phenomenon to measurable units, but to complement

such quantitative methods with narrative approaches. This focus on the patient narrative will provide clinicians with an insight into the patient's interpretation of the experience of symptom clusters, which is crucial to the development and delivery of effective symptom management interventions. This call for a focus on narrative symptom clusters is reflected in the literature, where it has been postulated that such approaches allow the development of 'patient-centred' rather than statistically driven interventions (Lopez et al. 2011).

Following on from this is the call for health professionals involved in the assessment and management of symptom clusters in patients with cancer to further explore the role of meaning in such experiences. Based on the findings of this study, meaning was central to the participants' experiences of symptom clusters and also the way that they understood and made sense of this phenomenon, with them often picking out symptoms that were of personal significance to them in the context of their lives. Therefore, the role of the 'sentinel' symptom as previously discussed in chapters 8 and 9 of this thesis warrants further investigation. Table 15 below provides a framework for clinical practice where the role of the sentinel symptom may be further explored in the

management of symptom clusters in patients with advanced lung cancer. As detailed below, a three step approach is advocated.

<p>Table 15: Framework for clinical practice for the management of symptom clusters in patients with advanced lung cancer – Management of the 'sentinel' symptom</p>	
<p>Pre-intervention: Patient assessment:</p>	<ul style="list-style-type: none"> • Assessment of current symptoms experienced (incidence, severity, distress, associated meaning, associations between symptoms) • Patient asked what symptom/s is/are of greatest concern to them and why? • Patient hierarchy of symptoms determined in partnership with the patient using responses gleaned above to identify sentinel symptoms.
<p>Intervention</p>	<ul style="list-style-type: none"> • Sentinel symptoms identified by patients as being of greatest concern prioritized and targeted using existing interventions
<p>Post-intervention: Evaluation</p>	<ul style="list-style-type: none"> • Assessment of current symptoms experienced (incidence, severity, distress, associated meaning, associations between symptoms). • Patient asked what symptom/s is/are of greatest concern to them and why? • Patient hierarchy of symptoms determined in partnership with the patient using responses gleaned above to identify sentinel symptoms • Observation of differences between pre and post intervention stages to evaluate effectiveness of intervention

Utilising this framework would provide clinicians with a tool to ensure that patient experience is central to the assessment and management of symptom clusters in clinical practice. As argued throughout this thesis, it is time for the study of symptom clusters in patients with cancer to widen its approach, away from the dominance of the biomedical model and reductionist methods of measurement, to one that also appreciates and acknowledges the importance of lay perspectives of illness. It is time for the study of symptom clusters in patients with cancer to bring the 'person' in.

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Appendices

Appendix 1: Patient Information Sheet

Part 1

Study title: The Experience of Symptom Clusters in Patients with Lung Cancer

Introduction

I am a PhD student undertaking a study which is looking at the experience of symptoms in patients with lung cancer and would like to invite you to take part in this study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The study aims to understand what it is like for people who have lung cancer to experience a number of symptoms at the same time. We are interested to know more about people's symptoms and what effect this has on people's lives. The study may help health professionals to improve ways in which they manage symptoms for people when they have a diagnosis of lung cancer.

Why have I been chosen?

You have been chosen because you have been diagnosed with lung cancer. We aim to have 10 patients taking part in the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you decide to withdraw at any time, or not to take part at all, it will not affect your care or treatment in any way.

What will happen to me if I take part?

If you agree to take part, you will meet the researcher who is conducting this study, who will ask to interview you 2 times over a period of 3 to 5 weeks. The interviews will normally take place in your home if that is convenient for you. If you would prefer they can also be held in a private room in the hospital.

Expenses and Payments

It is anticipated that the interviews will take place in your home or at the hospital. If your interview is being conducted at the hospital, the researcher will try to

arrange this at a time that you will be attending the hospital for another appointment. You will not be reimbursed for any expenses in relation to this study.

What do I have to do?

If you are interested in taking part in the study, you will be asked by your doctor or nurse at your hospital to sign a form saying that you agree for your contact details to be passed onto the researcher conducting the study. The researcher will then contact you to explain more about the study. If you agree to take part, she will ask you to sign a consent form and will arrange to meet you.

The researcher will first ask you to talk about in detail what cancer means to you. She will then ask you talk about your life and your experiences since being diagnosed with lung cancer, with a particular focus on the symptoms that you have experienced at this time. It is expected that it will take around an hour to take part in the interview. If you agree, the researcher will record the interview, to make sure there is an accurate record of the interview. Disks will be stored securely at the University of Stirling and no-one outside the research team will have access to them. At the end of the first interview, the researcher will ask you if you would agree to be interviewed three to five weeks later to discuss in more depth some issues that you may have raised during the first interview and any new matters that may arise. If you do not want to take part in a further interview, you will be thanked for your time and your treatment or care will not be affected in anyway. You are free to withdraw at any time if you decide you no longer wish to take part. If you do agree, the researcher will begin the next interview by feeding back their thoughts on the last interview; this is to allow you to check that they have an accurate account of what you have said. This table shows how many times you will be contacted during the study:

Week 1	1st interview
Week 3-5	2nd interview

What are the possible disadvantages or risks of taking part?

As you will be talking about what cancer means to you, your life and experiences of symptoms since being diagnosed with lung cancer, you may find this upsetting. If you did feel that taking part in the study was upsetting you, then you can withdraw from the study without having any effect on your future treatment and care. If you wish, you can discuss these feelings or concerns with your doctor or nurse. (Details to be inserted).

What are the possible benefits of taking part?

Although there are no direct benefits to you, taking part in this study will give you the chance to say what you think about your illness and the symptoms that you have experienced as a result of it. The study may help other people affected by

lung cancer in the future by helping us to understand people's symptoms and develop ways in which we can manage them better.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in part 2.

Will my taking part in this study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

Contact for Further Information

If you would like to talk to someone else before deciding to take part, or at any time during the study, you can contact Mrs Roma Maguire, Research Fellow, Cancer Care Research Centre, by phoning 01786 460063 or emailing roma.maguire@stir.ac.uk. If you would like advice from someone not involved in the study, you can contact [\(details to be inserted\)](#)

This completes part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions (Roma Maguire – 01786-46-0063). If you remain unhappy or wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained from the hospital. In the event that something goes wrong and you are harmed during the research study, there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have some grounds for legal action for compensation against the University of Stirling but you may have to pay legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my taking part in the study be kept confidential?

If you join the study, some parts of your medical records and the data collected for the study will be looked at by authorised persons from the University of Stirling. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research site.

All information which is collected about you during the course of research will be kept strictly confidential.

No-one will be able to recognise you from any report about the study – your name and anything which could lead to anyone being able to identify you will be removed.

Involvement of the General Practitioner/Family Doctor (GP)

The researcher is required to tell your GP that you are taking part in the study, but this will only be done if you agree.

What will happen to the results of the research study?

The findings of this study will be presented in a thesis which will be submitted by the researcher for the award of a PhD qualification. The findings will also be published in academic journals. You will not be able to be identified in any report or publication. You can receive a short summary of the findings if you wish.

Who is organising and funding the research?

The researchers is being organised and supported by the Cancer Care Research Centre at the University of Stirling.

Who has reviewed the study?

The Local Research Ethics Committee and the local Research and Development Office at [name of hospital] have reviewed the study and approved it.

Thank you very much for taking the time to read this information.

Appendix 2: Consent to pass on personal details

Title of Project: The Experience of Symptom Clusters in Patients with Lung Cancer

Name of Researcher:

I confirm that I give authorisation for (name of PI to be inserted) to provide (name of researcher to be inserted)from the Cancer Care Research Centre at the University of Stirling my contact details to contact me to discuss the above study.

_____	_____	_____
Name of Patient	Signature	Date
_____	_____	_____

_____	_____	_____
Name of Person taking consent (if different from researcher)	Signature	Date

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

Appendix 3: Patient consent form

Centre Number:

Study Number:

Patient Identification Number for the trial:

Title of Project: The Experience of Symptom Clusters in Patients with Lung Cancer

Name of Researcher:

Please initial box

I confirm that I have read and understand the information sheet dated September 2006(version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that interviews may be tape recorded. It has been explained to me that tapes and questionnaires will be stored securely and that I will not be identified by anyone outside the research team.

I agree to my G.P. being informed of my participation in the study

I understand that relevant sections of my medical notes and data collected during the study may be may be looked at by responsible individuals from the University of Stirling, from regulatory bodies or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

I agree to take part in the above study

Name of Patient	Signature	Date
_____	_____	_____

Name of Person taking consent (if different from researcher)	Signature	Date
_____	_____	_____

Researcher	Signature	Date
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When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

Appendix 4: Interview summary/reflexive notes

Patient ID:

Date:

Number of interview:

Completed by:

- What were the main issues or themes that struck you in this contact?
- Summarize the information you collected
- Anything else that struck you as salient, interesting, illuminating or important in this contact?
- What questions do you have in considering the next interview?
- How did you feel when doing the interview?
- Any other thoughts/comments regarding this interview?

Appendix 5: Examples of empirical studies of symptom clusters in patients with cancer (2001-2011)

Qualitative studies							
Author	Theoretical Framework	Study Aim/s	Design	Sample	Measures	Analysis (to determine symptom clusters)	Cluster findings
(Lopez et al. 2011)	Leventhal and Johnsons Self Regulation Theory (Leventhal and Johnson 1983)	To explore the explanations about the development and co-existence of symptoms and how patients attempted to self-manage them	Qualitative, longitudinal study design	Homogenous n=10	Semi-structured interviews, over four time points (beginning of treatment, three, six and twelve months later)	Content analysis	<p>Four major narrative clusters indentified from the data: Tiredness, sleeplessness, pain, depression and weakness</p> <p>Hair loss, ocular changes, body image, identity experience and anxiety</p> <p>Nausea, loss of appetite, taste changes, bowel function, weight changes and distress</p> <p>Numbness and tingling sensations in the hands and feet,</p>

							restlessness, sleeplessness and depression
(Molassiotis et al. 2010)	Not detailed	To explore the symptom experience of patients with cancer over a 1-year period from both the patient and informal caregiver perspective	Qualitative, longitudinal study design	Homogeneous n=17	Semi-structured interviews	IPA (Smith et al. 2009a)	Findings indicate that a cluster of interacting respiratory symptoms play a central role in patients' symptom experiences within the lung cancer population. The interviews also suggest that symptoms such as cough which are under-represented in research within this population may play an important role in patients' symptom experiences
(Molassiotis et al. 2008)	Not detailed	To explore the experience of chemotherapy related nausea in patients with cancer.	Qualitative, descriptive study	Heterogeneous sample n=17	Single, semi-structured interviews	Content analysis (Strauss and Corbin 1990)	Range of symptoms linked with nausea were described by patients, these were categorised as concurrent (those that were not consistently present with nausea) and associated symptoms (those symptoms that participants clearly described as temporally occurring

							<p>in conjunction with nausea).</p> <p>Concurrent symptoms (number of quotations): sleep disturbance (n=4), fatigue (n=7), bloating (n=2), sore throat (n=2), sweating (n=2), weakness (n=4), dizziness (n=1) and headache (n=2), flu like symptoms (n=3) and feeling hot and cold (n=2). Combinations of these symptoms were also present when nausea developed.</p> <p>Associated symptoms i.e. those clearly occurring in conjunction with nausea – burping (n=1) associated with a hot sensation (n=1), a 'feeling [of needing] to swallow, push things down' n=1) and regurgitation (n=1); intolerance of smells (n=1), taste disturbance (n=7),</p>
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							loss of appetite (n=15), vomiting (n=11) dry heaves (n=4). Frequently associated symptoms emerged including loss of appetite, vomiting and taste changes and they often occurred simultaneously suggesting a possible symptom cluster'
Quantitative Studies							
(Dodd et al. 2010)	Symptom Management Theory (Humphreys et al. 2008)	To determine whether: *subgroups of oncology outpatients can be identified based on a specific symptom cluster (pain, fatigue, sleep disturbances, depression) *these subgroups differ on outcomes (i.e., functional status, quality of life) *subgroup membership	Secondary analysis of data (T1 start of chemotherapy T2 end of chemotherapy T3 end of study)	Homogeneous Breast cancer n=112	*Worst pain scale (Miaskowski et al. 2006) *Piper Fatigue Scale (Piper 1987) *General Sleep Disturbance Scale (Lee 1992) *CES-D (Sheehan et al. 1995) *Karnofsky Performance Status (Karnofsky et al. 1948) *Multidimensional Quality of Life Scale (Ferrell et al. 1989)	Cluster analysis	At T1 and T2, four patient subgroups were identified: *ALL LOW (one or no symptom greater than the cut score) *MILD (two symptoms), *MODERATE (three or four symptoms), *ALL HIGH (four symptoms). At T3, three subgroups were identified: *MILD *MODERATE *ALL HIGH. Subgroups with high

		changes over time.					severity levels of all four symptoms had poorer functional status and QOL at each time point than other subgroups (p<0.001).
(Lui et al. 2010)	Not detailed	To explore the associations between a pre-treatment cluster (sleep disturbance, fatigue and depression) and longitudinal profiles of the same symptoms during chemotherapy	Quantitative , prospective, longitudinal study design	Homogeneous Breast cancer n=76	*Pittsburg Sleep Quality Index (Buysse et al. 1989) *Multidimensional Fatigue Symptom Inventory- Short Form (Stein et al. 1998) *Center of Epidemiological Studies – Depression (Sheehan et al. 1995)	ANOVA Pearson Correlation Analysis	*All women reported more sleep, fatigue and more depressive symptoms compared to baseline *Women with more pre-treatment symptoms continued to experience worse symptoms during treatment than those who began with fewer
(Cheung et al. 2009)	Not detailed	To characterize the patterns of symptom clusters among advanced cancer outpatients and to explore the impact of different cancer sites on these	Prospective, quantitative study design	Heterogeneous n = 1366	*Edmonton Symptom Assessment Scale (Bruera et al. 1991)	Principal component analysis Cronbach's alpha coefficient	*Cluster 1 – fatigue, drowsiness, nausea, decreased appetite and dyspnoea *Cluster 2- anxiety and depression Two clusters identified for each cancer site: *CNS:Cluster A –

		clusters					<p>anxiety, depression and wellbeing</p> <p>Cluster B – pain, drowsy, fatigue and dyspnoea</p> <p>*Head and Neck:</p> <p>Cluster A: anxiety, depression, fatigue, dyspnoea and wellbeing</p> <p>Cluster B: pain, drowsy, appetite, nausea</p> <p>*Breast:</p> <p>Cluster A: anxiety, depression, drowsy, nausea</p> <p>Cluster B: appetite, wellbeing, dyspnoea</p> <p>*Lung cancer:</p> <p>Cluster A: Anxiety and depression</p> <p>Cluster B: Appetite, wellbeing, pain</p> <p>*GI:</p> <p>Cluster A: Anxiety, depression, nausea, pain, drowsy</p> <p>Cluster B: Appetite, wellbeing, fatigue and dyspnoea</p> <p>*GU:</p> <p>Cluster A: Anxiety, depression, nausea</p> <p>Cluster B: Appetite,</p>
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							<p>wellbeing, fatigue and pain</p> <p>*Gynaecological: Cluster A: Anxiety and depression Cluster B: Appetite, wellbeing and fatigue</p> <p>*Haematological: Cluster A: Anxiety, drowsy, fatigue, dyspnoea Cluster B: Appetite, nausea</p> <p>*Anxiety and depression consistently clustered together in solid tumours regardless of disease type</p> <p>*Pain and drowsiness clustered together for cancers of the CNS and head/neck</p> <p>*Decreased appetite and poor general wellbeing clustered together for breast, lung, GI, GU and GYN malignancies</p> <p>*Cluster of anxiety, drowsiness, fatigue and dyspnoea was unique to haematological malignancies</p>
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(Finnegan et al. 2009)	Not detailed	To identify: *sub-groups of adult cancer survivors using self reports of frequency, severity and distress rating for 8 symptoms (lack of energy, worry, pain, difficulty sleeping, feeling irritable, feeling nervous, difficulty concentrating and feeling sad)	Prospective, quantitative study design	Heterogeneous n=100	*MSAS (Portenoy et al. 1994) *Health promoting lifestyle profile (Walker et al. 1987) *The Ferrans and Powers Quality of Life Index: Cancer III version (Ferrans 1990)	Latent variable mixture modules	Cluster of 8 symptoms identified: lack of energy, worry, pain, difficulty sleeping, feeling irritable, feeling nervous, difficulty concentrating, and feeling sad
(Kim et al. 2009)	Not detailed	To determine the occurrence rates for symptoms and the severity of symptoms at the middle, end and 1 month after the completion of radiotherapy treatment, to determine the number and types of symptom clusters at these time points to	Prospective, longitudinal study design	Heterogeneous n=160	*MSAS (Portenoy et al. 1994)	Exploratory factor analysis	Although not identical for all three time points, 3 relatively similar symptom clusters were identified in the study sample over time: *mood-cognitive cluster *sickness-behaviour cluster *treatment-related or pain symptom cluster

		evaluate for changes over time in these symptom clusters					
(Wilmoth et al. 2009)	Theory of Unpleasant Symptoms (Lenz and Pugh 2008)	To provide initial validation of a proposed symptom cluster of fatigue, weight gain, psychological distress, and altered sexuality in breast cancer survivors	Descriptive, cross sectional study	Homogeneous Breast cancer n=15	*Piper Fatigue Scale (Piper 1987) *Profile of Mood States (McNair et al. 1992) *Wilmoth sexual behaviours questionnaire (Wilmoth and Tingle 2001) *Demographic data form	Linear regression	Clustering of all symptoms observed in 7 patients Clusters of three symptoms occurred in 3 patients One patient only experienced one of the four symptoms
(Yamagishi et al. 2009)	Not detailed	To clarify the prevalence of physical and psychological symptoms and concerns among a representative sample of cancer patients receiving chemotherapy in the outpatient setting and to evaluate symptom clusters in this study population	Quantitative prospective, longitudinal study design	Heterogeneous n=462	*Brief screening interview for adjustment disorders (Akizuki et al. 2003) *Japanese version of the M.D. Anderson Symptom Inventory (Okuyama et al. 2003) *The EORTC QLQ-C15-PAL (Groenvold et al. 2006) *Impact thermometer for use in combination with the Distress	Cluster analysis	Three symptom clusters identified: *Fatigue and somnolence and Pain, dyspnoea, and numbness *Nausea, appetite loss and constipation *Psychological distress

					Thermometer as a brief screening tool for adjustment disorders and/or major depression (Akizuki et al. 2005) *Cancer Needs Questionnaire (Cossich et al. 2004)		
(Bender et al. 2008a)	Not detailed	To identify and compare symptom clusters in individuals with chronic health problems with cancer versus individuals with chronic health problems who do not have cancer.	Exploratory, secondary analysis of data	Heterogeneous n=746	*Comorbidity Questionnaire (Charlson et al. 1987) *CRCD Sociodemographic Scale	Exploratory factor analysis	Clusters for total sample: *cluster 1: shortness of breath, chest palpitations, chest pain, abdominal pain, back pain *Cluster 2: night sweats, fatigue, nausea and vomiting *Cluster 3: leg or arm weakness, generalised pain, joint pain, walking problems, balance problems *Cluster 4: weight loss, weight gain, loss of appetite, over-eating Cancer History: *Cluster 1: skin rash, itching, night sweats, constipation, dizziness

							<p>standing, abdominal pain, back pain</p> <p>*Cluster 2: fatigue, nausea, diarrhoea, generalised pain, sleeping problems</p> <p>*Cluster 3: leaking urine, frequent urination, walking problems, balance problems</p> <p>*Cluster 4: weight gain, over eating, shortness of breath, chest palpitations, joint pain</p> <p>No cancer history:</p> <p>*Cluster 1: shortness of breath, chest palpitations, chest pain, back pain</p> <p>*Cluster 2: night sweats, fatigue, nausea, diarrhoea, abdominal pain, sleep problems</p>
(Chow et al. 2008)	Not detailed	To explore the presence of symptom clusters in patients with brain metastases and if they change	Prospective, longitudinal study design	Heterogeneous n=170	*Edmonton Symptom Assessment Scale (Bruera et al. 1991)	Principal component analysis with varimax rotation Cronbach's	<p>Three symptom clusters found at baseline:</p> <p>*Cluster 1: fatigue, drowsiness, shortness of breath and pain</p> <p>*Cluster 2: anxiety and depression</p>

		with whole brain irradiation				alpha	*Cluster 3: poor appetite, nausea, and poor sense of well being
(Hadi et al. 2008a)	Not detailed	To validate the symptom cluster identified in a previous study (Hadi et al. 2008b)	Quantitative prospective, longitudinal study design	Heterogeneous n=57	*Brief Pain Inventory	Principal component analysis with varimax rotation	Two symptom clusters identified: *Cluster 1: worst pain and interference with general activity, normal work and walking ability *Cluster 2: interference with mood, sleep, enjoyment with life, and relations with others
(Maliski et al. 2008)	Not detailed	To identify symptom clusters that include urinary and erectile dysfunction among men treated with prostate cancer	Secondary analysis of data	Homogeneous Prostate cancer n=402	PCI-SF – quality of life questionnaire for men with prostate cancer (Litwin et al. 2004) Medical Outcomes Study Short Form, version 2 (SF-36) (Ware and Sherbourne 1992)	Four analytic approaches used: *Frequency and co-occurrence (symptom-based) *Correlations (symptom-based)	Composition of the clusters was not consistent Emotional distress and fatigue figured prominently in all analytic methods

						*Factor analysis (symptom based) *Cluster analysis (patient - based)	
(Olson et al. 2008)	Not detailed	To develop a causal model of the relationships between symptoms in cancer palliative care patients as they approach death and investigate the changing associations among the symptoms and between those symptoms and wellbeing	Secondary analysis of data	Heterogeneous n=82	Edmonton Symptom Assessment Scale (Bruera et al. 1991)	Structural equation modelling	*Model fit was acceptable and explained between 26% and 83% of the variation in appetite, tiredness, depression and wellbeing. *Drowsiness displayed consistent effects on appetite, tiredness and wellbeing. *Anxiety's effect on wellbeing shifted importantly, with a direct effect and indirect effect through tiredness at one month being replaced by an effect working exclusively through depression at one week.
Yeh et al, 2008	Not detailed	To derive symptom clustering in a large group of	Descriptive correlation study	Heterogeneous n = 144	*M-SAS Children (Collins et al. 2002) *Play Performance Scale for Children	Cluster analysis	Five clusters of symptoms identified: *Cluster 1: Symptoms related to

		<p>older paediatric patients with cancer in Taiwan and to examine whether each cluster differed based on gender, type of cancer and disease, pain and functional status</p>			<p>(Lansky et al. 1987) *Hospital records used to collect data on patient characteristics, disease information, demographic data collected from parents</p>		<p>sensory discomfort and body image (internal concerns) – dry mouth, itching, diarrhoea or loose bowel movement, numbness or tingling or pins and needles feelings in the hands or feet, changes in skin, feeling of being nervous, I do not look like myself *Cluster 2: Symptoms related to circulatory and respiratory system malfunction: shortness of breath, dizziness, swelling of arms or legs, cough, problems with urination *Cluster 3: Fatigue, sleep disturbance and depression: difficulty concentrating or paying attention, difficulty sleeping, lack of energy, feeling of being drowsy, feelings of sadness, worrying, feeling of being irritable, sweating *Cluster 4: Body</p>
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							<p>image (external concern) and eating difficulties: weight loss, hair loss, mouth sores, constipation or feeling uncomfortable because bowel movements are less frequent, difficulty swallowing</p> <p>*Cluster 5: Symptoms related to gastrointestinal irritation and pain: nausea, vomiting, lack of appetite, pain, changes in the way food tastes</p> <p>*Cluster 5: boys reported higher distress than girls ($p < 0.05$); patients with leukaemia experienced more distress in cluster 3 than patients with other tumours. Patients with pain reported statistically higher distress in all five clusters</p>
(Chen and Lin 2007)	Not detailed	*To validate the three clusters of symptoms identified in	Secondary analysis	Heterogeneous n=321	MDASI -T (Lin et al. 2007)	Confirmatory factor analysis	*3 symptom clusters (sickness, gastrointestinal, emotional) were

		<p>previous study (sickness, gastrointestinal, emotional) in a larger sample of patients. *To examine how four disease/ treatment variables (diagnosis, disease stage, cancer treatment and hospitalisation) were associated with the three symptom factors.</p>					<p>replicated in different sample *Higher scores for each cluster associated with poorer functional status *Metastatic disease, receiving concurrent chemotherapy and radiotherapy associated with poorer functional status</p>
(Chow et al. 2007)	Not detailed	To explore whether bone pain 'clusters' with other symptoms in patients with bone metastases	Quantitative ,prospective ,longitudinal study design	Heterogeneous n=518	Edmonton Symptom Assessment Scale (Bruera et al. 1991)	Principal component analysis with varimax rotation	<p>Three symptom clusters were identified:</p> <p>Cluster 1: fatigue, pain, drowsiness, and poor sense of well being Cluster 2: anxiety and depression Cluster 3: shortness of breath, nausea and poor appetite</p>

(Fox et al. 2007)	Theory of Unpleasant Symptoms (Lenz et al. 1997)	To describe the co-occurring symptoms (depression, fatigue pain, sleep disturbance and cognitive impairment), quality of life and functional status in patients with high grade glioma	Descriptive, correlational study	Homogeneous high grade glioma n=73	<p>*Cognitive Functioning Subscale of the Medical Outcomes Scale (Hays and Stewart 1992)</p> <p>*Depression Subscale of the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983)</p> <p>*The Brief Pain Inventory (Serlin et al. 1995)</p> <p>*The Brief Fatigue Inventory (Mendoza et al. 1999)</p> <p>*Sleep Disturbance Scale (Lee 1992)</p> <p>*Physical, Functional and Brain Subscales of the Functional Assessment of Cancer Therapy Scale (Weitzner et al. 1995)</p> <p>*The Fox Simple Quality of Life Scale (Fox 2004)</p>	Correlation Hierarchical multiple regression analysis	<p>Significant inter-correlations demonstrated between the co-occurring symptoms (depression, fatigue, sleep disturbance, cognitive impairment). (Depression and pain not inter-correlated).</p> <p>*Cluster 1: Depression, fatigue, sleep disturbance and cognitive impairment significantly correlated with quality of life</p> <p>*Cluster 2: Depression, fatigue, sleep disturbance, cognitive impairment and pain significantly correlated with functional status</p> <p>Depression accounted for 26% of the variance in quality of life, other cluster symptoms displayed minimal contributions</p> <p>Depression explained 56% of the variance in functional status and</p>
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							pain explained an additional 5%. Other cluster symptoms explained only 1% in variance of functional status
(Molassiotis et al. 2008)	Not detailed	To explore the experience of chemotherapy related nausea in patients with cancer.	Qualitative, descriptive study	Heterogeneous sample n=17	Single, semi-structured interviews	Content analysis (Strauss and Corbin 1990)	<p>Range of symptoms linked with nausea were described by patients, these were categorised as concurrent (those that were not consistently present with nausea) and associated symptoms (those symptoms that participants clearly described as temporally occurring in conjunction with nausea).</p> <p>Concurrent symptoms (number of quotations): sleep disturbance (n=4), fatigue (n=7), bloating (n=2), sore throat (n=2), sweating (n=2), weakness (n=4), dizziness (n=1) and headache (n=2), flu like symptoms (n=3) and feeling hot and</p>

							<p>cold (n=2). Combinations of these symptoms were also present when nausea developed.</p> <p>Associated symptoms i.e. those clearly occurring in conjunction with nausea – burping (n=1) associated with a hot sensation (n=1), a 'feeling [of needing] to swallow, push things down' n=1) and regurgitation (n=1); intolerance of smells (n=1), taste disturbance (n=7), loss of appetite (n=15), vomiting (n=11) dry heaves (n=4). Frequently associated symptoms emerged including loss of appetite, vomiting and taste changes and they often occurred simultaneously suggesting a possible symptom cluster'</p>
(Barsevic k et al. 2006a)	Not detailed	To test, through secondary analysis , a	Secondary analysis of data	Heterogeneous n= 295	*The General Fatigue Scale (Meek et al. 1997)	Hierarchical multiple regression	Mediation model failed in the intervention group

		<p>mediation hypothesis about the direct and indirect relationships between fatigue and depressive symptoms through a pathway including functional status</p> <p>Mediation hypothesis – proposed that functional status was a mediator between fatigue and depressive symptoms</p>			<p>*The Functional Performance Inventory (Leidy 1999) *The Short Form of Profile Mood States (McNair et al. 1992)</p>	analysis	Control group – part mediation reported (43%) of the total mediated effect – state that the mediation hypothesis was supported
(Fox and Lyon 2006)	Theory of Unpleasant Symptoms (Lenz et al. 1997)	To explore the prevalence and intensity of depression, fatigue and pain in survivors of lung cancer, to examine the relationship of symptoms in a cluster and to examine the relationship of the symptom	Secondary analysis	Homogeneous Lung cancer n=51	<p>*Questionnaires – Short Form 36 Health Status Survey *Quality of life – Fox Simple Quality of Life Scale(Fox 2004)</p>	Pearson’s correlation and multiple regression analysis	Two significant correlations were depression and fatigue. The cluster explained 29% (p<0.01) of the variance in quality of life in lung cancer survivors

		cluster to quality of life					
(Glaus et al. 2006)	Not detailed	To explore the occurrence and frequency of menopausal symptoms in women with breast cancer undergoing cancer treatment and to investigate their relationship with fatigue	Prospective, cross sectional study	Homogeneous Breast cancer n=373	*Clinical Checklist for Patients with Endocrine Therapy(Hopwood 1998) *International Breast Cancer Study Group Linear Analogue Scales addressing the side effects of hormonal treatment and coping with disease and treatment (Bernhard et al. 1997)	Cluster analysis	Cluster of menopausal symptoms identified – hot flashes, weight gain, tiredness, decreased sexual interest and vaginal dryness
(Hoffman et al. 2006)	The Theory of Unpleasant Symptoms (Lenz et al. 1997)	To examine the relationships among pain, fatigue, insomnia and gender while controlling for age, co-morbidities and stage in patients newly diagnosed with lung cancer	Secondary analysis	Homogeneous Lung cancer n=80	*Cancer Symptom Experience Inventory (Given and Given 2002) *Co-morbidity questionnaire (Katz et al. 1996)	Multinomial log-linear modelling used	A model containing all main effects (two-way interactions of pain and fatigue, pain and insomnia, and insomnia and gender , and the three-way interaction of pain, fatigue and insomnia along with the three covariates (age, comorbidities, and stage of cancer) was a good fit to the data. *Parameter estimates indicated that a statistically significant

							effect from the model was the three- way interaction of pain, fatigue and insomnia – co-variates did not make a difference. *Symptom cluster exists consisting of pain, fatigue and insomnia
(Miaskowski et al. 2006)	Not detailed	To identify subgroups of outpatients with cancer based on their experiences with the symptoms of fatigue, sleep disturbance, depression and pain; to explore whether patients in the subgroups differed on selected demographic , disease and treatment characteristic and to determine whether patients in the subgroups differed on two important	Descriptive, correlational study	Heterogeneous sample n=191	*Karnofsky Performance Status Scale (Karnofsky et al. 1948) *Lee Fatigue Scale (Gay et al. 2004) *General Sleep Disturbance Scale (Dorsey et al. 2004) *Center for Epidemiological Studies-Depression Scale (CES-D) (Carpenter et al. 1998) *Multidimensional Quality of Life Scale Cancer (Ferrell et al. 1989) *Descriptive numeric rating scale for worst pain intensity (Jensen 2003)	Clusters analysis	The cluster analysis procedure identified 4 relatively distinct subgroups of patients. *Those who reported low levels of all four symptoms (35%), *Those who reported high levels of all four symptoms (15%) *Those who reported high levels of fatigue and low levels of pain (35%) *Those who reported low levels of fatigue and high levels of pain (15%). Patients categorised in the 'all low' subgroup reported higher quality of life scores than those in the other three subgroups

		patient outcomes; functional status and quality of life					($p \leq 0.01$). No differences were found between patients in the high fatigue and low pain and low fatigue and high pain groups. Patients in the 'all high' subgroup reported lower quality of life scores than the other three subgroups ($p \leq 0.001$).
(Reyes-Gibby et al. 2006)	Not detailed	To evaluate whether respondents of a survey of a nationally representative sample of adults aged 50 or over with a history of cancer had excess risk of pain, depression and fatigue. To compare the clustering/co-occurrence of symptoms between those with a history of cancer and those without.	Secondary data analysis	Heterogeneous sample n=17,210	*Single questions on pain and fatigue. *Center for Epidemiologic Studies on Depression (CES-D). (Carpenter et al. 1998)	Chi-square tests. Multivariate analysis	Statistically significant differences ($p < 0.001$) were observed for the occurrence of pain and fatigue cluster, fatigue and depression cluster and pain-depression and fatigue cluster between those with and those without a history of cancer Those with a history of cancer higher risk of experiencing symptom clusters
(Wang et al. 2006)	Not detailed	The aim of this study was to	Quantitative longitudinal,	Homogeneous Lung cancer	M.D.Anderson Symptom Inventory	Mixed effect	Four clusters of symptoms with unique

		<p>establish a profile of the development of different symptoms over the time of therapy and to examine symptom related functional interference in patients with non-small cell lung cancer undergoing concurrent chemotherapy</p>	<p>prospective study design</p>	<p>n=64</p>	<p>(Cleeland et al. 2000)</p>	<p>growth curve models</p>	<p>temporal relationship to the course of CXRT were identified. *Cluster 1: rates of change for both pain and sore throat steadily and significantly increased in severity over the course of therapy and then decreased in the post therapy phase *Cluster 2: showed a rapid increase in therapy related GI toxicities, including nausea and vomiting, in the early and mid CXRT periods. *Cluster 3: non-specific symptoms that included fatigue, lack of appetite, drowsiness, sleep disturbance, dry mouth and distress, reflected an increase in severity in both the early and late therapy periods. *Cluster 4: included affective symptoms such as sadness, cognitive issues (difficulty</p>
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							remembering), and other disease or treatment related symptoms (shortness of breath, cough and numbness) – no major change in severity over the course of treatment *Cluster 3: has the highest predictive value for total interference with daily activities followed by cluster 4, cluster 1 and cluster 2.
(Chan et al. 2005)	Theory of Unpleasant Symptoms (Lenz et al. 1997)	To assess the existence of a symptom cluster involving breathlessness, fatigue and anxiety in patients with advanced lung cancer undergoing palliative radiation	Quantitative prospective, longitudinal study design	Homogeneous Lung cancer n=27	Visual analogue scales measuring the intensity of breathless, anxiety and fatigue	Pearsons product-moment correlation Spearman coefficients	The correlations between the three symptoms were moderately strong (r=0.49 – 0.75). The proposed symptom cluster had high internal consistency across T0-T2. These data support the notion that the symptoms may be viewed as a symptom cluster
(Ridner 2005)	Not detailed	To compare the quality of life and symptoms between breast cancer survivors	Cross sectional, mixed methods study	Homogeneous Breast cancer n=64	Quantitative data: *sociodemographic information, medical data, BMI, arm extra cellular	Logistic regression equations Qualitative	A symptom cluster that included alteration in limb sensation, loss of confidence in body,

		<p>who have developed and undergone treatment for chronic lymphoedema with those who have not developed lymphoedema</p>			<p>fluid volume. *Quality of life: FACT-B (Cella 1997) and FACT-B Plus 4 Subscale (Coster et al. 2001) *Upper Limb Lymphoedema Scale(Launois and Alliot 2000)</p> <p>Symptoms: *Symptoms Checklist (developed by the PI)</p> <p>Depressive symptoms: *(Carpenter et al. 1998) *Profile of Mood States (POMS-SF) (Curran et al. 1995)</p> <p>Qualitative data: Patients with lymphoedema responded in writing to the question: during the past week what other difficulties have you experienced</p>	<p>data: transcribed, content analysed, peer reviewed and categories identified.</p>	<p>decreased physical activity, fatigue, and psychological distress was identified</p> <p>Symptom cluster findings were supported by responses to the question posed – ‘when responses were categorised, ten themes emerged – psychological distress, altered arm sensation, fear of injuring arm, fatigue, poorly educated health professional, sleep disturbance, infection, treatment limitations/benefits, secondary impact on the body, and change in wardrobe/jewellery use. Interestingly, as in the quantitative instruments, pain and depression were absent from these narratives.</p>
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					because of your lymphoedema?		
(Carpenter et al. 2004)	Not detailed	To compare sleep quality and disturbance, fatigue and depressive symptoms between breast cancer survivors and healthy women experiencing hot flashes and to examine relationships among sleep and remaining variables (fatigue, depressive symptoms, and frequency of hot flashes)	Cross sectional, descriptive, comparative study	Heterogeneous n=30	*Menopausal status – Massachusetts Women’s Health Study (Brambilla et al. 1994) *Sleep: Pittsburg Sleep Index (Buysse et al. 1989) *Fatigue: POMS-SF (Curran et al. 1995) *Depressive Symptoms: (Sheehan et al. 1995)	Non-parametric Spearmann’s statistics	Global sleep scores were significantly positively correlated with fatigue and depression, but not with flash frequency
(Gift et al, 2003)	Theory of Unpleasant Symptoms (Lenz et al. 1997)	To determine whether symptom clusters identified at the time of diagnosis remained 3 and 6 months after diagnosis	Secondary data analysis	Homogeneous Lung Cancer n=112	Physical Symptom Experience Tool (Given et al. 1993)	*Cronbach’s alpha *Pearsons r correlations *Pearsons product-moment correlation *ANOVA *Logistic regression	The cluster of 7 symptoms (fatigue, weakness, weight loss, appetite loss, nausea, vomiting, altered taste) remained over the course of lung cancer and is an independent predictor of the patient’s death.
(Wilmoth	(Barton-	To identify the	Literature				Analysis of the

et al. 2004)	Burke 1997) postulated a cyclical relationship between fatigue and sexuality	symptom cluster of fatigue, weight gain and altered sexuality caused by the treatment of breast cancer	review				literature suggests a link among the symptoms of fatigue, weight gain and altered sexuality.
(Dodd et al. 2001b)	Model for Symptom Management (Dodd et al. 2001a)	To determine the effect of the symptom cluster of pain, fatigue, and sleep insufficiency on functional status during three cycles of chemotherapy	Secondary analysis	Heterogeneous n=93	*Disease and Treatment Questionnaire (developed and used by investigative team) *Karnofsky Performance Status (Karnofsky et al. 1948) *The Quality of Life Cancer (QOL-CA) version (Padilla et al. 1990) *Demographic questionnaire (developed and used by investigative team)	Two-stage hierarchical multiple regression	*KPS at time 1, age, pain and fatigue were significantly correlated with KPS at time 2 *Inter-correlations between symptoms (pain, fatigue, and sleep insufficiency) were low (pain to fatigue $r=0.22$, pain to sleep insufficiency $r=-0.06$) and fatigue to sleep insufficiency $r=-0.13$). *The overall hierarchical multiple regression model explained 48.4% of the variance in functional status *KPS at time 1 explained 30.8% of the variance in KPS at time 2 *Second step, KPS at time 1 partialled out from KPS at time 2, the four independent

							variables were all predictors in the change in functional status between time points 1 and 2. Age explained 11.8% of the change, pain explained 10.7% of the change, fatigue explained 7.3% of the change. Sleep insufficiency statistically was not significant only explaining 1% of the change.
(Given et al. 2001)	Not detailed	After adjusting for age, and number of co-morbid conditions, does site and stage of cancer predict functional limitations prior to diagnosis? When compared with age adjusted national norms on physical functioning, how	Mixed methods, cross sectional	Heterogeneous n=826	*Co-morbid conditions identified through a patient interview *Demographic, disease treatment related characteristic from case notes *Medical Outcomes Study 36-item Short Form (Ware and Sherbourne 1992). *At intake interview patients asked to recall physical	Polychromous logistic regression	Pain, fatigue and insomnia has a consistent and negative effect on losses in functioning unrelated to the patients treatments or their co-morbid conditions

		<p>well does age, stage of cancer, number of co-morbid conditions, treatments and clusters of symptoms explain changes in physical function between 3 months prior to and 6 to 8 weeks following diagnosis?</p>			<p>functioning level 3 months prior to diagnosis of cancer and at current time (6-8 weeks following diagnosis) *Symptom assessment, patient asked to report if within two weeks prior they had experienced pain, insomnia or fatigue plus other symptoms</p>		
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Appendix 6: Example of analysed transcript

Exploratory codes	Example of data analysis: Original Transcript	Emergent themes
<p>General Inquiry</p> <p>Wanting to make sure that interview is for a good cause – altruistic reasons?</p>	<p>Dan Interview 2</p> <p>[tape starts with patient talking]</p> <p>DAN: So what are you going for with this?</p> <p>DAN: It's a PhD, that I'm ...</p> <p>DAN: PhD?</p> <p>ROMA Yeah, I'm trying to ... hopefully</p> <p>DAN: And what do you get when you get the ... is that you home and dry?</p> <p>ROMA Eh, well, I don't know if it's home and dry but ...</p> <p>DAN: But you know what I mean, aye</p> <p>ROMA It's, it's, it'll help things along hopefully, it'll help ...</p> <p>DAN: You?</p> <p>ROMA Primarily it'll help ...</p> <p>DAN: You? Us?</p> <p>ROMA ... people like you</p>	

<p>Wanting to make sure that it will help other people like him?</p> <p>Wants to makes sure that the results of the study are used to help others like him?</p> <p>Making sure his data will be used – not sure why he is saying this – some distrust from past experiences?</p>	<p>DAN: Oh right, aye</p> <p>ROMA ... you know to understand about your experiences ...</p> <p>DAN: Uh huh, aye, aye</p> <p>ROMA ... the symptoms that your experiencing to try and ...</p> <p>DAN: And will you move about when you get this PhD or will you be studying at, staying permanent in a permanent position, in, in a unit somewhere?</p> <p>ROMA It's, it's the Cancer Care Research Centre, so we do a lot ...</p> <p>DAN: Oh right</p> <p>ROMA ... a lot of research around this area, so ...</p> <p>DAN: Aye, aye, aye, aye</p> <p>ROMA I'd like to stay there</p> <p>DAN: Aye so it's, it's ...</p> <p>ROMA all tied in</p> <p>DAN: It's all tied in, aye, aye, aye. You're no drifting away fae something ...</p> <p>ROMA No</p> <p>DAN: No, no</p> <p>ROMA No, if I do I'll make sure I use it, I would never ...</p>	
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<p>Does he really not care or is he just saying this?</p> <p>Praising health professionals- putting them on a pedestal – why? – reliance on them to live in light of being diagnosed with a life limiting illness</p> <p>Does he really think this – they way he is describing the system is like a conveyor belt – has to think this way to cope with what is happening to him</p>	<p>DAN: Aye, aye</p> <p>ROMA ... you've given me your time</p> <p>DAN: Aye, no, no, I wondered what you were ... I'm only asking the question like, at the end oh the day I'm no caring what you dae wi' it, it's been a pleasure geing you my advice but I just wondered what you were going to do wi' that</p> <p>ROMA Mmm mmm, well it's hopefully to understand what's going on and then try and manage symptoms better, understand from your perspective ...</p> <p>DAN: Aye, being the patient</p> <p>ROMA ... which to me is really, really important</p> <p>DAN: Aye, aye, aye being the patient is important I suppose</p> <p>ROMA Oh it is</p> <p>DAN: I mean you go tae, you, you got to various consultants and folk eh, they're very nice but they meet you and a quarter of an hour later they're meeting somebody else, I mean I don't know how eh, they remember you at times, because you're sitting talking away to them, they're no reading their notes and all of a sudden they'll come and say to you, oh you had this, that and the next thing on such and such a date, and your saying, how the hell does he remember, the amount of peoples he's meeting in a week, he can pin point you to a certain article or a certain thing, it amazes me how a, any consultant of any ... can go back and say, Ok, he has'nae had time obviously tae read your notes that day because it's boom, boom ... you know it just, basically well I'll</p>	<p>Reliance on health professional to live</p>
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<p>Comfort in feeling that health professionals are dedicated to him – does he feel that his life is in their hands? Coping mechanism?</p> <p>Changes tone and direction of the interview – does this a lot when talks about things that he finds upsetting –does not like to display any weakness....</p> <p>More important things on his mind than the last interview?</p>	<p>say quarter of an hour, every quarter of a hour, it's no, no really that but you know what I mean, they're maybe, you've got so many patients in the morning, so many patients in the afternoon, well he has'nae got time tae read aw your minutes and then the next day he's away somewhere else, so he's reading someone else's notes and it amazes me just exactly</p> <p>ROMA How they just pick it up</p> <p>DAN: How they pick it up. Photographic memory is, is a one way of putting it, I don't think it's photographic memory, I think it's dedication</p> <p>ROMA Yeah, yeah. I think to do the job ...</p> <p>DAN: Dedicated</p> <p>ROMA ... you've got to be dedicated to it</p> <p>DAN: Dedication (sounds emotional)</p> <p>ROMA It's good to know that and know that isn't it ...</p> <p>DAN: Right, where are we going</p> <p>ROMA OK, so it's just to say thanks for agreeing to take part ...</p> <p>DAN: No problem</p> <p>ROMA ... in this next interview em, and first of all I'm just going to ask you em, can you tell me about any thoughts that you've had concerning the things that we talked about last time, anything that's ...</p> <p>DAN: Do you want the honest truth? Never gave it a thought</p>	
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<p>Wanting to please – be a good patient – scared of getting things wrong?</p> <p>Uses humour a lot – coping</p>	<p>ROMA OK</p> <p>DAN: I'm being perfectly honest wi' yae, you walked oot that door and I says a very nice lady, I enjoyed the talk wi' her and I never gave it another thought</p> <p>ROMA OK</p> <p>DAN: So you might be disappointed in that</p> <p>ROMA No, no, it's just to see if there's anything ...</p> <p>DAN: No</p> <p>ROMA ... like you know when I, when I went away</p> <p>DAN: If I've gave you the wrong answer ...</p> <p>ROMA No, there's no right or wrong answers</p> <p>DAN: ... I'll apologise, but I never gave it one more thought</p> <p>ROMA Oh that's ...</p> <p>DAN: And I had to say to J today, you were coming tonight, I says and eh, we'll have another wee chat, and it wasn't till you phoned last week that you even entered my mind</p> <p>ROMA That's good</p> <p>DAN: Hmm ... so ...</p> <p>ROMA That's, that's fine. Em ...</p> <p>DAN: You can go hame any time you like [laughs]. No, no, naw ...</p>	<p>Humour – coping</p>
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<p>mechanism</p> <p>Cancer never goes away – suggests significant events have happened over the past few days. Realistic about his prognosis</p> <p>Will try and help – want to help – altruism</p> <p>Giving researcher place of being the professional – modest in what he can offer</p>	<p>naw it's just ...</p> <p>ROMA It's just to say you know if I went away if there's anything you thought of ...</p> <p>DAN: Naw</p> <p>ROMA "maybe I should have mentioned that or did I tell the girl that, or ..."</p> <p>DAN: No, no. It's just what you said earlier, it's the way of life. You came, we had a talk, I've still got it when you went away, I never gave it another thought. I gave a lot of other things a lot of thought like you know but, I never gave that a thought, there's a lot of things, other things had happened like you know ...through this day [4.08] but eh, again before the end oh the night [4.12], no ...</p> <p>ROMA OK</p> <p>DAN: ... so fire away ...</p> <p>ROMA So, so as I said really what I'm going to do is just really have a wee chat with you and mention some things that you mentioned in the last interview and ask you to talk about them a bit more or to explain them to me or things likes that</p> <p>DAN: If I can</p> <p>ROMA Yes</p> <p>DAN: [laughs], I maybe no</p> <p>ROMA Yeah, just see how it goes</p> <p>DAN: I'll maybe no...you can pit your ain words in if I tell you, I'll tell</p>	
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<p>Worst disease of all because it kills you?</p> <p>Childhood experiences of cancer framed negative perception of disease now?</p> <p>Associates death and breathlessness as being inter-linked - ?reason why symptom is of such significance to him? Talks about it a lot in interviews</p> <p>Childhood experiences of cancer – STIGMA - – avoiding people with the disease/ associated with a bad death-sticks in his mind – affects the way he views the disease currently?</p> <p>Tries to distance self from way he treated people with cancer as a child – embarrassed at this past actions?</p>	<p>you, you can pit yer ain words in [laughs]</p> <p>ROMA But they'll all be yours - <i>honestly</i></p> <p>DAN: Oh right, oh well</p> <p>ROMA Em, so you right, you'll remember last time we, we had a chat and the first I said em, you know what does cancer mean to you, that was the first question, that's ...</p> <p>DAN: It's a hell oh a disease, I've told you, I'm still saying that (laughs). What, well when you were younger it wis' the hell oh aw diseases and in actual fact as far as I'm concerned, it's the hell oh aw diseases because it either kills you, makes you breathless, well it inevitably kills you, but so does a million and one other things, but really it's the last thing you want. I mean at one time if you mentioned you had cancer – Jesus Christ it was like a red rag to a bull, I mean everybody gies you a wide berth, you know that yoursel I mean, let's be honest about it like, I mean, eh, you walk doon the street and somebody'll say – oh he's got cancer, Christ you were nearly across the road at one time and I'm talking in older day, I'm not talking, I'm talking when I was a wee boy like, so I'm going really back. I mean this is before cancer, they did'nae have cures in these days but it wis, as far as I'm lead to believe and brought up it wis the hell oh aw diseases so that's, that's the only explanation, it's always stuck in my mind, you know when you were a wee boy at the school – oh Joe, Joe, Joe so and so's got cancer or, it could be cancer of the leg...it could be cancer anywhere, I mean there's a million and one cancers as you know, I mean we've no aw got the same, if we hud aw the same, we'd aw be the same, we're aw Jock Thompson's bairns, but we're no aw the same eh, so, eh, that's the only explanation and me saying that, that I can give you, if you can take anything oot oh that ...</p>	<p>Fear of death</p> <p>Childhood experiences of cancer - stigma</p> <p>Salient symptom – breathlessness – fear of death</p> <p>Childhood experiences of cancer - stigma</p> <p>Fear of death</p>
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<p>Points out that everyone is an individual – is this because he wants to distance himself from the stereotypical persona of a person with lung cancer – still associates an element of stigma with the disease?</p> <p>Suggests these view points were very strong as a child – hard to shift such thoughts now? Reason why they permeate his experiences now?</p> <p>Avoiding people with cancer when he was a child – uses humour – is he embarrassed about this? Tries to point out that he was a child at the time – not fully responsible for his actions?</p> <p>Does he feel an element of stigma – he has something that no one else wants?</p> <p>Using social comparison to cope – everyone has to get something – he is not different – does this make him feel</p>	<p>ROMA Mmm mmm</p> <p>DAN: ... you know it's just what's kinda more drummed into you but, what your lead to believe, is that a better word?</p> <p>ROMA Mmm mmm. From when you were a wee boy?</p> <p>DAN: Aye, aye, it's just. You're at the school and you're going to school and Joe "so and so's" got this....and your saying, you know you, you did'nae know any better, you know ... it was, just what I've said [laughs] ... don't go near him, [laughs], you know, he's goat something naebody wants ... well you have goat something naebody wants really at the end oh the day, but if you don't get this you get something else I suppose....in this present day and age because there's a million and one things in the world that's every bit as bad</p>	<p>Childhood experiences of cancer - stigma</p> <p>Stigma and lung cancer</p> <p>Social comparison -</p>
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<p>more accepted?</p> <p>Social comparison – there are other diseases that are just as bad</p> <p>Changes tone to cancer charities – is this because he wants to feel like something is being done to help him – people are looking for cures – HOPE? Feels comfort in thinking this?</p> <p>Now values life – precious to him, in light of fear of death?</p> <p>Praising people who are involved in care of people with cancer – his lifeline?</p> <p>Value of life – angry that people making decisions re drugs put a price on a life – shows how much he values being alive</p>	<p>....and they are trying very hard, I mean give Cancer Research due ... eh, credit where it's due, they are trying hard....and in saying that, I'm talking about ca., and I may be talking out..this may no be known...I reckon Cancer Research are doing a marvellous job but there's some oh the organisations bleeding it because that money that's going in, is'nae aw going tae it as far as I'm led to believe, which I think is wrong. I would gie to Cancer Research numerous times but I'm led to believe on certain circumstances all your donations are not going to where it's supposed to be. I may be wrong, I'll retract my statement if I am wrong, but that's my feelings. You'll know better than me and I'm no asking you to say yes or no...you know, but there is certain organisations collecting for Cancer Research and it's no going but they are doing a marvellous job and there is more and more people dedicated like yoursel and em, oncologists and eh, pharmacists fighting to get em, pills, treatment, various types of treatment for various cancers and they are winning. I mean you, you read I the paper there – oh there's a new, this new things out eh, but it's costing too much, what's - <i>don't get me started</i> – what is a, what's a life worth? I mean hell when I got the Tarceva I could understand that it's a lot of money, so therefore they've goat to apply tae the health board, irrespective of what health board it is, you've got to apply. Can we give this patient the tablet because it's costing X amount oh pounds per month? My argument to that is, it should'nae matter a damn what it costs a month. What's that man's life or that ladies life or that kids life worth? You cannae pit a price oan life. So why do we need to go doon that road, this is maybe ... am I, am I going away oaf track here</p>	<p>coping</p> <p>Value of life – fear of death</p> <p>Reliance on health professionals to live</p>
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<p>Identified as a cancer patient due to his rash – did not have to tell her, she knew....</p> <p>Angry at the way that the man was treated – value of life and you can't put a figure on it?</p> <p>Links cancer prognosis with his breathlessness – marginal increase and breathlessness worsens - talks about this symptom a lot – salient symptom from all the others he is experiencing?</p> <p>Use of 'we' a lot of the time – feels health professionals are in a team with him – he is not alone?</p> <p>Does not want the answer because he does not really</p>	<p>ROMA No but, can you tell me why you feel like that – why?</p> <p>DAN: Well if you, if you need something why do you no get it? Instead of saying and apply, I mean in England there just em, no that awfy long ago, there was a thing in the news there that eh, it was costing too much eh, for the tablets, I mean I, and in actual fact I went to [name of hospital] for one CT scan and there was an old chap sitting next to me, he'd came up fae Man., he stayed in [town hospital is situated in] but he was on his own, and he was getting his treatment in [name of hospital] and he came up tae [town hospital is situated in] for his CT scan and he was sitting right next to me and his daughter said to me – are you on Tarceva? I says yes, she says aye I thought that wi' the kinda, ken I had a light rash, and the old boy says aye, I'm oan it tae, he says eh, it cost me £3,000 he says, I had to buy my first lot, I says – you what? He says I had to buy it, he says I'm, I'm down in Manchester he says, they'll no give me it. So that old guy, noo he, Christ ...he must have been late 70's, early 80's I would reckon and he'd tae pit oot 3 grand to buy this Tarceva. Noo tae me, possibly the guys worked aw his days like you know, <i>this is me getting on my high horse by the way</i> [laughs]. That gentleman should have deserved a bit of quality of life as he put it and he's, he's needing tae fork oot 3 grand hoping, hoping that it's going to cure him, we don't know. When I was on the Tarceva, my cancer marginally increased and that's, well it was just today that I learned that they reckon this is where part of this breathlessness is now coming in, cause at Christmas my cancer was stable, it is now stable again like the last, at mid-term eh, chemo it was stable. They don't know what it is the day like you know but em, and I said to J about it, she says well we don't really know but she says that marginal increase could cause enough, you know tae, tae offset your breathing slightly – we're only guessing, because see at the end of the day you'll never actually get the answer to say it was that or it wis'nae that, but we're no really wanting the answer was it that or was it that...</p>	<p>Value of life – fear of death</p> <p>Breathlessness – salient symptom</p>
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<p>want to know all the detail – some denial?</p> <p>All he cares about if his breathlessness can improve – scared of what will happen if it doesn't? Only cares about this symptom? Not the others?</p> <p>Trying at the same time to blame other causes apart from his cancer? Coping?</p> <p>Protecting health professionals – needs them to live?</p> <p>Trying to reassure himself that if this treatment does not work for his breathlessness something else will?</p> <p>Shocked at how quick his treatment was stopped?</p>	<p>aw we're wanting the answer is can the breathing come back to what it was prior to that, it could have [hiccups] been possibly [sorry about the hiccups], it could possibly have been nothing tae dae wi' it anything, it could have been something, it could have been a bug fae somewhere else, because I wis oan em, I went tae my ain doctor and I was on antibiotics oh Christ for about 12 weeks and they ch., they gave us eh, started oaf wi' obviously Amoxycillin and then they upped it to something else, did'nae much improve it, upped it to something else ... it's trial and error but the doctors and various staff, they, they cannae eh, it's no like a motor car that's broken doon eh, we'll pit a new bit in it and it'll go, you've goat tae just work through the, the various systems oh pills like you know and if you get one, fair enough, you're lucky, you may need two, you know but you haven't time ..you get there in the end... I think, you know, so you give them due, but again back to the pills eh, I think you should get them if you need them, that's my philosophy</p> <p>ROMA I think that's fair enough</p> <p>DAN: [laughs] and on that note, when the minute they knew that my Tarceva wis'nae working they stopped, Dr R was on holiday at the time and the consultant at the time, I just forget the name he says, stop them as of now – now. At that particular time I had a box oh 150 mil Tarceva's with two out it, I had a box wi' 100 mil no opened and I had a box half, 16 tablets oot oh a box, all in this house. Now the box that wis'nae opened, was never touched, the seal was still oan it, they aw came individually wrapped in foil, every tablet, in a box, every wan oh</p>	<p>Breathlessness – salient symptom – only concern is this symptom</p> <p>Minimising symptoms – coping</p> <p>Reliance on health professionals to live</p>
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<p>Linked to previous comment – angry that peoples’ lives are determined by money and cost</p> <p>Feels so strong about it would have broken the law....</p> <p>Thinks he is talking about things that are not of interest to the researcher – always wants to get things right – scared of what happens if he gets things wrong.</p>	<p>they tablets went back and was destroyed – noo tae me, that is where the National Health Board, irrespective oh where it is you live, it’ll be Scotland, England, Ireland or blood Wales is losing their money. Why did that pack, why did that box eh, that was never even opened, the carton was never even opened, it was sealed, why did that need to go and get destroyed? There's naebody can gie me that answer, that’s where the money’s wasted. Instead of saying can we afford tae gie this guy the tablet, the tablets that’s not being used, genuinely not being used and not being opened should go back oan the shelf, because naebody’s touched the damn things, it’s a farce. And I've, and I've said to the wife often, see that old guy that was doon there, see if I had have been sitting, I know it would have been against the law tae gie me them, but id have laid them doon and says – oh I’ve accidentally left them there there a box oh Tarceva’s – I never gave you them. Three grand!</p> <p>ROMA It’s a lot of money</p> <p>DAN: [15.11] you would’nae have walked away and left three grand there if you were’nae going to be buying them. Again it wis'nae, I didn’t break the law but somebody professionally could have took that box from me put them tae him and says – there you are, professional I’m saying, not willy nilly, like a consultant. Because I mean, you’ve even got X-ray machines noo that can X-ray, pin point things, the just stick that box through the X-ray, they can tell you whether that box has been tampered wi' already ... you know there is ways, there is various ways and means oh saving money on the health ... again I’m away, I’m maybe away miles fae you now</p> <p>ROMA No, no it's good to hear your, your views on what you think of things that are related to what you’ve had to go through</p> <p>DAN: That’s my thing oan the tablets</p>	
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<p>Not blaming the health professionals caring for him – they are his life line?</p> <p>Patients would not interfere with tablets as they are their life line?</p> <p>Why would he think that health professionals would not trust their patient – has he himself thought about this?</p> <p>Wants to be a good patient</p>	<p>ROMA Mmm mmm, mmm mmm</p> <p>DAN: OK, it's different if you open a bottle, a bottles away like ken but ... on, that, that ... in my family, eh we were just talking about that on Sunday, my son and my daughter were just talking about the money that was wasted within this whole household, now this is only one household – how many more households? And it's nothing tae dae wi' the consultant that's, that's prescribing the pills, it's just he's prescribing the pills tae his, the best of him knowledge, they are not doing with you, so therefore he's got to cancel them, so ... give him a fighting chance</p> <p>ROMA Mmm mmm, mmm mmm</p> <p>DAN: ... by giving them to someone else, stick them through a scan ...</p> <p>ROMA Something like that</p> <p>DAN: There's naebody that going to give you a wee bloody pill, stick something in it, to go to aw the both eh, I mean we're, we being patients wi' cancer, the last thing on your mind is to interfere wi' tablets, it's the last thing oan your mind is to start interfering, oh I've to stoap taking them, you shove them in the drawer, you don't start saying, oh I'll dicky there up or something like, you know because that's basically what's ... they're saying that we cannae use them because you've had them ... [laughs]</p> <p>ROMA I know it's ...</p> <p>DAN: ... but carry away, I'll no interrupt you any longer</p> <p>ROMA No, no as I say it's good to hear what you think about things, that's important, so no that was good to hear</p>	<p>Reliance on health professionals to live</p>
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<p>Angry at drug companies and system for preventing people from accessing drugs that may help them – feels that they do not value life?</p>	<p>DAN: Aye, aye, I think the expense oh the National Health is really needing to be ...</p> <p>ROMA Looked at</p> <p>DAN: ... looked at, from that perspective, where there's a tablet or a box oh tablets, whether it be any kind oh tablet, if it's never been opened – don't waste it</p> <p>ROMA Put it back in the system</p> <p>DAN: Aye</p> <p>ROMA aye</p> <p>DAN: Aye. I mean there, there a firm there I think it was last week, they were geing yae, they were giving yae stuff for, is it breast cancer .. he, and if it did'nae work eh, you were to get it for nothing</p> <p>ROMA Aye, id heard that on the news</p> <p>DAN: ... I mean that's something, that's something phenomenal isn't it? ... tae, tae say that if this disnae work, you can have it for nothing, that's a drug company, so I mean, they cannae dae that ... there's got to be a, it's no a con but there's got to be something somewhere along the lines, I mean a drug company cannae make drug, drugs are very, very expensive - as we know and I don't know bloody much, but I know this much – they are expensive to develop, it's the developing stages I think that the drug...so therefore em ... how can they dae it? But it's some ...</p> <p>ROMA It is ... no, no, it's a good point</p> <p>DAN: Oh aye, aye, aye</p>	<p>Value of life – fear of death</p>
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<p>Scared of causing upset – wants to do things right?</p> <p>Apologetic – does not want to cause any upset</p> <p>Realistic about prognosis</p> <p>Taking treatment to live – but also wants some quality to his</p>	<p>ROMA Em ...</p> <p>DAN: But as I said ... they're so far advanced now</p> <p>ROMA mmmmm....ok</p> <p>DAN: Sorry about that wee burst, out-burst</p> <p>ROMA No</p> <p>DAN: [laughs]</p> <p>ROMA It's good to hear what you think about different things, it all shapes your experience that you are, so that's, that's great. Em, just go harping back to what we were talking at the start you know when I was saying what, what does cancer mean to you ... em, when we were talking last time you said you know if you'd got it, you'll always have it ...</p> <p>DAN: Mmm mmm ... well I will anyway</p> <p>ROMA Minimise it as much as possible...</p> <p>DAN: Uh huh, aye minimise it as much as possible</p> <p>ROMA can you, can you explain a wee bit more about why, why you said that?</p> <p>DAN: Well you don't want to, you don't want tae have it, but when you've goat it, I'm going for chemo at the moment and the reason I'm going for chemo is to minimise the cancer, so that...long-term, I'll live longer, I might be a bloody pest, but I'll live longer and that is why you want to minimise the cancer, your hear, you're trying to ...well you get to my kind of age you, you've maybe had your quality of life but your still looking for a bit of quality of life, even in retirement you're looking</p>	
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<p>life as well? Does he have this?</p> <p>Social comparison – others like him – comfort in this Going through chemo just to live – sounds like he has no quality of life at this time – despite him saying earlier that he would like to have this – primacy of just being alive? Living another day takes over everything else</p> <p>Body tells him how he is – when body not ‘normal’ indicates to him that things are not good- suggests that he feels that his body is ‘alien’ to him – concurrent symptoms in determining the self –gastritis, heartburn</p> <p>Conscious of changes in his body due to treatment – symptoms not normal – not familiar with what is happening to his body – body is a gauge for him determining how he is? Linking up symptoms – stomach burns, then ‘thrapple’ – gullet burns?</p>	<p>for a bit of quality of life, but I mean there's ... again, how many folk sees retirement, some folks only a fortnight in retirement, so I mean eh, naw you don't want it, you cannae get rid oh it, if you cannae get rid oh it, the next best thing tae dae is <i>minimise</i> the problem. And mini., and as far as I'm concerned I'm going to take chemo, I'm going through aw this, I definitely do not have quality of life, that is one thing I do not have but, I'm prepared tae pit up wi' the life I've goat to minimise it. I mean there's some days em, Christ you could eh, you could run a mile because you don't just feel like, there's 9 or 10 days oot oh 20, you could say, oh Christ I don't just feel right today, like your stomach could be kinda a burning sensa., you know there's things in your body that you cannae, I could'nae really explain to you but, you know it's, your tastes no right, your feels no right, you know there's just something no there, or something that should'nae be there eh, it's, but they say eh ... normal, it's no normal ... does that maybe help you? So therefore ...</p> <p>ROMA Can you explain a wee bit more about that, about “not normal”</p> <p>DAN: ... well I've seen me lying in bed and my stomach rumbles and eh, your, your all of a sudden, your stomach begins to burn and your, your thrapple [gullet] begins to burn but your, you've no got heart-burn, you know it, it drifts away, so whether it's the chemo, the drugs your on, or what it is, you don't know but your, your body must change wi', wi' what your taking...you know, I mean your getting chemo there eh, what does, what, what chemo does to me, will probably no dae the same to you, you know although we could be on the chemo....each body has a different function or each body functions differently, can I put it that way, so therefore what affects you, may no affect me, and what affects me, may no affect you, so therefore as I say em, up to well, up to lately I've never been put off my food and I go into hospital there and I see folk that are like beanpoles, cannae eat, cannae dae this ...</p>	<p>Reliance on health professionals and treatment to live</p> <p>Social comparison - coping</p> <p>Symptoms and loss of sense of self - gastritis, heartburn - body not normal</p>
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<p>Pointing out his is different again – trying to show that he is better/healthier than other people with a similar illness?</p> <p>Views weight loss as a discrediting characteristic – wants to distance himself from people with cancer who have this symptom – does he stigmatise them? See's weight loss as preventing people from doing things – he still works, it's important to him – scared if he loses too much weight it will stop him from working?</p> <p>Linking weight loss with breathlessness</p> <p>Using concurrence/clusters as a means of finding cause of his symptom</p> <p>Views weight loss as being due to his breathing – once again breathlessness comes to the fore in his narrative-demonstrates how meaningful this symptom is to him. Blames much of the impact of his disease on this symptom</p> <p>Scared as he views weight loss with loss of functioning and nearing death?</p>	<p>I've lost a wee bit oh weight in the last month, I'll be perfectly honest wi' yae, I have lost, maybe about 6 pund, the last month, but that's through the breathing and God knows what like, you know, cause your were'nae feeling like eating. I mean my wife makes a dinner there and she pits it doon in front oh me, she says a sparrow would eat mare some days, because she'll phone up and say what are you wanting, oh id like this for my dinner, id like that for my dinner, you drive hame and you drive in, then you pit your bag doon, you pit your bag and take you shoes oaf, wash your hands, wash your face, which I have'nae done, by the way em ... and she pits the dinner oot in front oh yae and by the time you've goat it in front oh yae, you don't want it, you take a look at it and you kinda peck at it like a blood hen, you know ... you eat a wee bit but your only eating quarter because, I don't know whether it was something in the mind, or in the body or that, but you just don't feel like eating that. And you've been looking forward to this aw day like, you know. I mean you have a plate oh soup, maybe tatties and steak or something like you know, and, and you'll be eating ... well I've seen me actually eating a steak and all of a sudden, you're eating the steak and then all of a sudden the meat begins to roll as if you cannae swallow it and that puts you right oaf, so there when you start that, instead of cutting it wee and eating it again, you throw it to the side, so there's aw they wee kinda, I mean I suppose it's perseverance wi' yourself but eh, you say to yourself, Christ I'm no hungry now you know ...</p>	<p>Symptoms and stigma – weight loss – salient symptom</p> <p>Linking symptoms – weight loss and breathlessness – concurrence for finding cause of symptom</p> <p>Breathlessness – salient symptom</p>
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<p>Tries to please wife by asking for he to cook things? Does not want to be a burden to her?</p> <p>Does he disassociate his body from his mind – why? – can control his mind but not his body?</p> <p>Does not like his family seeing this – if he does not eat it is overtly visible to others – can't hide the impact of his disease from them? (see other quote where he says he tries to hide his symptoms to protect his family). Is this why it makes it worse for him as everyone can see?</p> <p>Does not like people to nag him – see above- visibility to others of his disease and prognosis – weight loss so significant as like breathing you need to eat to live – linked with fear of death?</p> <p>Weight loss also significant to Dan – is this because this symptom too is like</p>	<p>ROMA And how do you feel when your, you feel that, you know the dinners put in front of you and you don't feel hungry any more ... what, what, what are you thinking?</p> <p>DAN: No well, you've got much of a chance in this house because they all moan at you, " why are you no eating? ... " like, you know, and I'll say for God's sake gie us peace I'm no wanting any mare, because my sons there, my daughters sometimes there, the wife's there and she will say, Christ is that aw your eating like you know, so you don't get, you don't get forgetting that you haven't ate it, because everybody roond about you is reminding you and that makes me even worse [laughs]</p> <p>ROMA But why, why?</p> <p>DAN: I don't know why, it's just a case of ... I don't want it, you know and they'll no take no for an answer, you know ... (laughs)...so ..</p> <p>ROMA Could you, you know in the last interview you mentioned weight loss a few times ...</p>	<p>Being a burden- not wanting family to see symptoms</p>
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<p>breathlessness – you need to eat to live? No mention of other symptoms really –do they not concern him?</p> <p>Knows things are not getting better – not denying how he is on this occasion</p> <p>Trying to blame weight loss on not eating due to chemo – linking up symptoms-weight loss and anorexia - contrasts to earlier where he blames it on his breathlessness – some denial here?</p> <p>Linking weight loss and breathlessness</p> <p>Concerned re weight loss – links it to prognosis</p> <p>Trying to provide reasons for him to believe that it is not his cancer which is causing the weight loss – it's due to him not eating foods he did before?</p>	<p>DAN: Aye, aye, aye ... I'm bad this time</p> <p>ROMA Can you tell me a wee bit more about why you talked about ????</p> <p>DAN: Well, I wis'nae eating, that's why I ... that's the only reason I've lost weight, because I wis'nae eating, you know eh., loss oh appetite if you like through – possibility chemo. I think it must do. But I, I've kept average weight right through up till, [25.09] average weight right for a year and a half, it's aw about the 75 kilo mark, I'm doon tae about 72 and a half the now so I've lost two and a half kilos in about the time I've seen you, this is about 5, 6 weeks, because I know for a fact up until the weekend there, I wis'nae eating and I've taken a, an awfy and I can't answer the question so don't even, ask me why ... but all of a sudden I've taken a sudden hate to chips, I don't know why but I just hate ... and I could eats chips ?????? [25.45] then all of a sudden, I was oot oan Friday night for a meal, there were 24 oh us there and I had a steak and E had a steak and I ate half the chips and normally my plate would have been clear [26.01] you'd have thought the locusts had have went through it and all of a sudden,.....[26.06] even on the Saturday night we go oot for a fish supper, or, I'm saying a fish supper, a chippie – nae chips, single fish, you know ... or if I had chips just get us, just get us em, just you buy it ... whatever your buying we'll just half the chips, they just .. I don't know why, I can answer the question, I don't know, I've just suddenly taken a steele to chips, potatoes – aye, nae problem, any shape or form – potato...no problem</p> <p>ROMA No chips</p> <p>DAN: ... but chips – nope and I can't answer your question</p> <p>ROMA Well..that's fine...</p> <p>DAN: I'm being perfectly honest wi' yae, I haven't got an answer to it,</p>	<p>Weight loss-salient symptom</p> <p>Linking up – weight loss and lack of appetite</p> <p>Linking up symptoms – weight loss and breathlessness</p> <p>Minimising symptoms - coping</p>
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<p>Interesting in the way that he does not talk about symptoms all together – experiencing lots of symptoms but dialogue commonly focuses on symptoms which are of significant meaning to him – seems to be their association with impending death – picking out salient symptoms form the rest?</p> <p>Does not want to go there to find an answer – in denial – a ‘fad’? Does not like not knowing the cause of his symptoms – can’t control it?</p> <p>Feels comfort that his is improving – fact that others have commented on this reinforces to him that this must be true – trying to convince himself and the researcher of this?</p> <p>Breathing again – blames this solely on his condition worsening – scared that he was going to die – once again link with breathlessness and death. Very important as he spontaneously talks about this</p>	<p>again bearing in mind... for all I know [laughs], no, you know. No I'm joking em, no, they're just they kind oh fads, it's a fad for want of a better word, it's a fad, I suppose if somebody pit them doon and says right, eat that...you would dae it, it's a fad [laughs]. But naw, naw I wis, I'm, I'm ... definitely up to the weekend there I wis'nae eating but I'm, I'm, it is improved, I can assure you, but it's been commented on [laughs], so whether the wee change on Friday night made a different or no, change of company ... you don't know ...</p> <p>ROMA Mmm, I'm pleased</p> <p>DAN: ... you get into it, y., y., y., as I said I was going doon, the breathing was getting to me and I was gradually sliding the wrong way, I'm usually sliding – “uphill” but wi' the breathing getting tae me I was sliding doon hill, but I was feart I was going to slide too far doonhill, you know what I mean</p> <p>ROMA Can you tell me a wee bit more ...about...</p> <p>DAN: Well eh, during the xx [name of nurse] and..... and aw that says</p>	<p>Minimising symptoms coping -</p> <p>Breathlessness - salient symptom - links to prognosis</p> <p>Coping positive -</p>
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<p>symptom</p> <p>Positive thinking – feels that this has some therapeutic benefit – see previous quote in interview</p> <p>Breathing affecting him – scared that it will come to a point when they can no longer treat his breathlessness – feels at this point death will be very near – afraid of this</p> <p>Comes to this point – jokes he would commit suicide – but then states that he is jesting – shows how significant this symptom is to him</p> <p>Uses humour a lot when talking about issues which he finds upsetting</p> <p>Changes subject – talks about how he needs humour to cope with what his happening to him</p> <p>Social comparison – coping – others who are worse than him</p> <p>All that matters to him is that he is still breathing – still alive – is this at whatever cost? Breathing and life...why sentinel to him</p>	<p>it was your attitude, your approach that's kept you up you know eh, and with this breathing getting to me and so...[makes gasping sound] it does get you down, you say to yourself, and what and, and they'll say to you, we'll maybe no can dae much fur yae em, it's just through the illness and your saying to yourself, Jesus Christ if that's the case I'll jump oaf ... I know that I'm telling it to you, but I don't really mean it, I'll jump oaf a brig and dae away wi' masel then you know, rather than this hinging our yae and, and I said the other day...and I got for my last chemo this week, next week, I says to her what happens efter that wi' the breathing, I says do I get a Calor Gas can tied tae my back, ken [cracks joke], I'm still joking about it like, you know but, seriously deep down it is very serious like you know em, but you've goat tae keep your pecker up by joking about things like, you know because if everybody was dull in doldrum, the world would be a hellish place, you've goat to have a bit of laughter in life and your actually make, your basically keeping your ain perk up by making a joke by saying, well I don't want a hose stuck up my nose, kind of thing like you know ... [laughs], you know he was like that [demonstrates], [29.09] because actually your making a joke regarding yourself, I've, I've seen other folk oh my god... you feel very sorry for people...it's a way oh life ... em, if you have to get it, you've to get it ... it's the only way to walk one fit in front oh the other then you dae it ... and folk's say to me, how are you this morning, I'll say fine .. eh, aye no bad I says, how are you, ah nae use oh complaining, naebody listens like you know or eh, och I walk along the road and I'm still breathing, so I take it I'm still here like, you know, just ... you know somebody said to me, I says well I walk some other ??????? how are you this morning? I says I woke up this morning and I'm still here, so ... another day ... and that's the way I've looked at it, throughout. It's no until I wake up in the morning and I'm still breathing, I'm still here, the mans daing his joab, he's keeping me alive [laughs] and hopefully he'll keep me alive a long while. Because as I said to you the last time, I asked him one day outright, I says how long has I got to go?, he says how long have I got, he says eh, I could jump in front of a bus the morn and be deed, I says well that is very true, but the ?????????????????????? I could jump in front</p>	<p>attitude</p> <p>Breathlessness – salient – fear of death</p> <p>Humour – coping</p> <p>Social comparison – coping</p> <p>Breathlessness – salient – need to breathe to live</p> <p>Social</p>
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<p>Makes him angry – he wants to do this but his body won't let him – sense of loss at the person he was and the person he is now</p> <p>Previously talks about having cancer and minimizing it and now talks about there being a cure – in denial to an extent?</p> <p>Talks about breathlessness being out of control - using his instincts to try and help himself – shows how primitive function is to him</p> <p>Trying to convince himself that he is better as his breathing is better</p> <p>Loss of sense of self – breathlessness preventing him from even undertaking the most basic of tasks</p> <p>Putting people with medical knowledge on a pedestal – needs them to live – reliance on them?</p>	<p>forward and says I'll still dae it ... you know, it does, well mine does anyway ...</p> <p>ROMA And when you get angry what are you, what are you thinking</p> <p>DAN: Naw, no you don't get angry ... well ?????????? says Christ almighty here we go again like, you know ... what, there'll need to be a cure for this ... but there probably, well there might be a cure I reckon my breathing's better this week than it was last week, because last week, oh Christ it was really I mean, I was standing for 5 minutes, I walked fae here to that gate I've to stand at the gate for 5 minutes to get ... and I mean really stand and dae nothing and if I was lying in my bed and I got breathless, I could'nae lie, I had to sit up, feet out the edge of the bed, it probably did'nae ... well I'm no medically minded but as far as my mind was concerned it telt me get my legs our the side oh that bed and sit on the edge of the bed and breath, I might no, I might no get as much breath lying, but as far as I was concerned, in my mind when I was lying I wis'nae getting an intake of breath the same as you were sitting up, I might be right and I might be wrong, you'll ken better than mmm mmm, being medically minded, I think you get more breath intake sitting up than you dae lying doon</p> <p>ROMA What were you thinking when you were feeling this breathlessness?</p> <p>DAN: Oh Christ, you were thinking, is it your last minute? Naw, no really like you know but, your saying to yoursel Christ I hope this disnae last too bloody long or if this gets worse they'll need tae dae something real, you know. Oh aye it's, it's just, that's the kind of stage</p>	<p>Breathlessness – salient symptom - loss of sense of self – basic activities affected</p> <p>Fear of death breathlessness – salient symptom</p>
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<p>Breathlessness – scared he was going to die – longer it lasts appears the threat of death becomes greater.</p> <p>Something real suggests that if it lasts he can't deny what is happening anymore that he may really die this time-reason why so salient to him</p> <p>Breathlessness – you need to breathe to live – reason why this symptom is so meaningful to him</p> <p>Scared of not doing things right – scared of the consequences?</p> <p>Last week was the worst experience of all – scared him?</p> <p>Constant presence of this symptom – others he has talked about have been transient in nature- chronicity of his breathlessness linked to the meaning that it holds for him?</p> <p>Glad he does not have pain - points out that morphine is not for pain - ? associates pain</p>	<p>your at like, you know, what do we do next like, you know ... but what dae you dae next if you cannae get a ... if you cannae get a breath, Christ you might as well no be here...you'll no be hear, cause it's the breathing that keeps you going, and if you get to the stage that you have to crawl, it's nae life, it might come to that, you know don't know like you know, we'll cross the bridge day by day and as far as I'm concerned I'm going back up the hill – the day. Am I geing you the wrang answers the day?</p> <p>ROMA You don't give me any wrong answers, I told you ... it's your, your story, honestly...that's what I am interested in...</p> <p>DAN: aye, naw well that's em, naw the breathing, the breathing was really eh, I've been short oh breath for a, a, a number oh month, but really last week was the daddy, when I had to say to him, eh, look you'll need tae, and that's when that lady doctor said I would'nae know what to give you and in actual fact it was Dr R that prescribed the tranquil., the tranquilisers and the em, oral ... Christ ...</p> <p>ROMA Morphine</p> <p>DAN: ... morphine</p> <p>ROMA Morphine</p> <p>DAN: Now the oral morphine he says is not for pain, I says no, I've no got any, I've nae pain, I have nothing – see if I could breath, id be perfect within myself – perfect</p>	<p>Fear of death</p> <p>Breathlessness – salient - chronicity</p> <p>Breathlessness - sentinel symptom -</p>
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<p>with death?</p> <p>Very strong quote - ‘...see if I could breathe, I'd be perfect within myself - perfect...’ - demonstrates how sentinel breathlessness is to his experiences - does not talk about any of his other symptoms in the same way - hierarchy of symptoms?</p> <p>This quote demonstrates how he views his breathlessness as being significantly different from all his other symptoms - he does not appear to be as concerned about other symptoms - is this because they are more amenable to treatment - transient, don't last long - he does not link them to death?</p> <p>Takes two tablets and this symptom is sorted - not the same case with his breathlessness - does not</p>	<p>ROMA Why...why do you think that?</p> <p>DAN: Because I know, my body's fine. OK I've got these wee burning sensations but I have'nae had them since I had the steroids and morphine and, and I'm taking pills to augment, you know you take your em, it's a tablet in the morning, a tablet at night, I've to take two a day because oh the, oh the em, the tablets I'm taking during the day, the steroids, you've goat to take one for your stomach, so that's possibly settled my stomach oot ... the [tries to think of name of tablet]</p> <p>DAN: Omeprazoles?</p> <p>ROMA Omeprazole?</p> <p>ROMA Yeah, yeah</p> <p>DAN: I take one in the morning and one at night, so possibly that's ironed oot, possibly when I had the heartburn or, or that, possibly would'nae hae the burning sensation if I was getting Omeprazoles I would'nae have had it, I'm just saying - possibly, not, I wouldn't have had it - possibly, so therefore that may have eliminated that factor but since I've been oan them em, and the steroids eh, he reckons this will open the airways, my own doctor doon there, she was a German</p>	<p>picks out from all the rest</p> <p>Breathlessness salient symptom - body is fine if he does not have this symptom - suggest does not view other symptoms in the same way</p>
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<p>have the same impact on him</p> <p>Had a lot of medical knowledge for a lay person – uses lots of medical terms when describing his condition</p> <p>Exercises are not what he wants? Wants something more definitive to treat his breathlessness?</p> <p>Giving health professionals their place – not criticising them – needs them to live?</p> <p>Is he trying to convince himself that his breathing is better – once again disassociating mind from body – his mind may say his breathing is better but is his body saying this as well? Is he trying to convince himself?</p> <p>Marginal difference – sounds like he is trying to convince himself that this is the case</p> <p>Gauges how he is base on his physical functioning</p> <p>Trying to cope with what is</p>	<p>doctor, she I went to her because of the breathing... because of the reasons, she says I don't think it's antibiotics your needing, she says I think your needing to go and see your oncologist, she says he'll give you something for your breathing ... she said and she mentioned something, she says there's em, exercises you do ... it could be your lung lying against a, an air vent ... an air ... an air ... <i>an air vent</i> ... [corrects himself], an air tube, you know she said it could be pressing slightly and curtailing the flow of air, she says and there is em, exercises you get and I says – "exercises?", but I didn't argue because I mean, she's a professional and she says go to your ... I says well I just ... it so happens to chance that I'm going tomorrow, she says well ask him tomorrow and she says if you've got any problems come back to me, she says and I'll write a letter, bit I, I don't have any problems at [name of hospital], I cannae praise them enough, I can't ... id pit [name of hospital] on a pedestal, really – I can't praise them enough. So I had nae problems there and that's when I got this, aw this stuff and that was only last Tuesday, Tuesday ... a week since I started taking them and I find if not true reflection but in my mind...my breathing is partial better than it was and that's me taking them for a week, so they may only be kicking in by now so, I don't know, we'll keep taking them, I've got 10 days, she says she would see me next week when I got for my second lot of chemo, if I require mare I'll get them, so if it's improving, I'll gladly take them. But in my mind there is a marginal difference in my breathing. I can walk that 10, 15 yards further than I wis at this time last week and no get breathless, so to me that is a difference, so they may be working, they will be working no doubt. I've no, I've no, I've nae, nae qualms about it not working, but you've goat tae gie the thing time ...</p> <p>ROMA Mmm mmm, yeah</p> <p>DAN: ... like a flower, a flowers got to grow, so, you've goat tae gie it</p>	<p>Reliance on health professionals and treatment to live</p>
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<p>anxiety</p> <p>Scared of hurting family when he is breathlessness- uses third person - has this happened in the past?</p> <p>Distress associated with this symptom</p> <p>Unintentionally -once again loss of control with breathlessness - genuine - wants to convey that he is not putting this on</p> <p>Scared of being a burden</p> <p>Gets to stage when his breathlessness is so bad that it impacts on others appears to be intolerable to him</p> <p>Scared of reaching that point in his illness - however sense that he knows that this day is likely to come...</p> <p>States once again how he hopes he never reaches this stage- demonstrates how much this thought distresses him/ how scared he is</p> <p>Use of 'we' again - he is not alone</p>	<p>could hurt somebody unintentionally through a panic attack, trying to get air, a genuine simple thing, so I mean that's, you know I would'nae like that scenario if you like to have a, a, a, ah need air.... and your, your, your automatic instinct is to go outside - for what reason?, nobody knows, but everybody's instinct is - outside. There's air outside, there's nae air in the hoose, there's air outside, it's the same bloody air I the hoose if you open the windae, maybe no as much but you know, so that's the concern if you were, if you were getting to the stage that you had no breath, you'd really get angry wi' the folk roond about yae and get narky, you know. I don't know, I don't know it, it's another, it would be another adventure if you want for a better word and one I hope never to cross ... [slight pause] ... that's as ??????? as I can pit it</p> <p>ROMA OK</p> <p>DAN: ... I hope I never cross it ...</p> <p>ROMA Mmm mmm</p> <p>DAN: Mmm mmm? Does that</p> <p>ROMA Yes</p> <p>DAN: hmm, hmm</p> <p>ROMA em, when we were talking about breathlessness last time</p>	<p>nearing...?</p> <p>Being a burden - symptoms - wants to protect family</p>
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<p>If he can find out the cause of his breathlessness then he can control it – make him feel better? Uses concurrence as means of trying to find out the cause of a symptom – how people make sense of the clusters they are experiencing?</p> <p>Links breathlessness to gastritis</p> <p>If it's his stomach then the threat posed by his breathlessness lessens?</p> <p>Blames it on a one off event – helps him cope with what is happening to him</p> <p>Lots of medical knowledge again – using terms health professionals would use</p>	<p>as well you were saying that when you were breathless, you were saying is it my stomach that's causing the breathlessness or is it the cancer?</p> <p>DAN: Aye well we don't know that, there naebody can answer that</p> <p>ROMA Can you tell me a wee bit more about why, why ...</p> <p>DAN: Well that's why I was saying about this burning sensation ...</p> <p>ROMA Mmm mmm</p> <p>DAN: ... you know did I have an infection in ... when, when I went ... I still maintain I've never been right eh, since, your just getting the very same story as you got the last time by the way, since I got the CT scan on the Monday and the, and the chemo the next day way back at the new year, I reckon that was my downfall [banging sound], and I don't give a monkey who says it, I reckon that was my ... to get the one thing one day and the one thing the next day. Noo they may be two completely different things, one might not contract the.... you know it might just be a ... it's happened, but I reckon that is the time that my stomach changed. Whether it was wi putting the dye through, which disnae go through your stomach, well maybe it does go through your stomach ... your ... well everything goes through your stomach at the end of the day I suppose, and I think wi' the dye going through it and the chemo the next day my innards, for what oh a better word – no ma stomach, ma innards never got a chance, they got blasted wi' too much stuff aw within 24 hours and my, well I might have gent., I might have a gentle stomach, I don't know what I've goat, you know what I mean? So possibly my stomach or my innards, if you like, could'nae cope wi' the in., influx oh the two things within the 24 hours, you know, so I've never actually been able tae throw that oaf, but I can't prove that and I'll no even be trying to prove it...because they're daing their best tae help you, so why put an obstacle in somebody's road and say, I should'nae have had that...it's, it's, done, dusted, water under the</p>	<p>Concurrence finding out cause of symptoms</p> <p>Linking up symptoms – breathlessness and gastritis</p>
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<p>Blaming health professionals on his stomach symptoms but then at the same time pointing out that he is not criticising them – protecting health professionals -lifeline</p> <p>Does not want anyone else to hear him questioning his treatment/care – fear of what would happen – needs health professionals to live</p> <p>Good patient – wants to protect health professionals</p>	<p>bridge – end oh story. But in my, back oh my mind and it'll always be in the back oh my mind, but I will never ever question it outside this house and I'm talking to you and it's oan that [points to recorder]</p> <p>ROMA Yeah, but it's all, you know it's all anonymous sort of thing</p> <p>DAN: I know that, but I'm just saying to you, that other people would chase it, I will never chase it – never</p> <p>ROMA Just, you know when you, when you were talking about your, your breathlessness and the cause of it, I'm just interested to know why ...</p> <p>DAN: ???</p> <p>ROMA ... why, why you're questioning is it your stomach and ...</p> <p>DAN: Aye well ...</p>	<p>Reliance on health professionals and treatment to live</p>
<p>Using clustering to determine concurrence of symptom -</p> <p>Using logic – cancer is static – so breathlessness must be due to something else (his gastritis?) – does he really believe that his cancer is static – is his body telling him otherwise?</p> <p>Modesty – giving health professionals their place</p>	<p>ROMA ... or your ca., ???</p> <p>DAN: Well I questioned this further back than last week tae eh, why and I questioned it the day, why is it if my cancer is static ..am I suddenly breathless? You know, in my joab if something's static, it lies there in a bloody corner and does nothing, you know so if it's why has my body all of a sudden became breathlessness come fae, because that cancers static, but I know I'm maybe, I'm maybe too "thick", for want oh better words that I'm no picking this up because, when it's static I maintain that it's no daing anything but it's, it's dead wood so why is it altering the breath? It must be coming fae somewhere else ...</p> <p>ROMA Right</p>	<p>Clustering to determine cause of symptoms</p>

<p>Body is telling him that things are not good – breathlessness is still bad – trying to find out where it is coming from so that he can have more control over it? Using clustering as a means of doing this...</p> <p>Now trying to attribute breathlessness to old age – coping/denial? Tries to convince himself but he cant</p> <p>Uses humour when talking about emotive topics</p> <p>Pounding – suggests treatment significantly impacts on him but then states the reverse by demonstrating how he does not need to be hospitalised, treatment quick – suggests impact is minimal</p> <p>Comparing self to others to cope?</p> <p>Trying to build positive perceptions of himself – how he can still drive, pointing out that he is still okay</p>	<p>DAN: ... and that's where the tire., that's where, that's where I'm getting the tie up, if people, you know ... does that maybe, you know this word static to me is – <i>nothing's happening</i>; but something's happening to me, so where is this that's happening tae me, coming fae. There's half saying aye – your static, this half's saying yer no static so is there something in this half that I don't know about like you know? So that's where the ...</p> <p>ROMA mmmm....</p> <p>DAN: I'm, I'm throwing balls in the air, pitting three up and probably getting 5 doon, or pitting 3 up and getting four doon, you know this is where my thoughts are coming fae, is it coming fae somewhere else, that's the only thing I can say tae yae, it's possibly no coming fae anywhere else, it's just, as time goes by, we do get breathless in old age ... [starts to laugh] ... would be a simple answer...but naw there's this, everybody's got their own thoughts on various things and that's just basically what I can tell you, so that's where I'm getting the, the left oh the right if you like of the two scenarios, likes is it coming fae my stomach, is it coming fae my ... cannae be coming fae my cancer, my cancer's static so it's goat tae be somewhere else. But your body does take a bit oh pounding during em, treatment and I've been very fortunate that I've had treatment, but I've never ever needed to stay in a hospital overnight and get aw this 24 hour jabs and Christ knows aw what like you know, I'm, I'm in and oot in an hoor, an hoor and a half max...if it's busy, and I'm very, very, I've been very, very fortunate, I mean very, very fortunate to have what I've goat, be in the position I'm in, talk about it, walk in, see the consultant, I walk in the morn and get my Tarceva and at half past 3 I'll drop back oot and I'll jump in the motor and come home. It has never ever stopped me from driving home from treatment, the chemo has never ... the wife did it the first twice and I says there's a waste oh time, I'm as well driving masel she would stay in the motor anyway, she was driving the motor but I was sitting in the passenger seat driving the motor, cause that's my style, I</p>	<p>Minimising symptoms – coping</p> <p>Humour</p> <p>Social comparison – coping</p> <p>Coping – work and normality - link to sense of self</p>
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<p>Feels good that he can still drive – positive perceptions – makes him feel that things are not so bad – trying to bring back his sense of self</p> <p>Goes back to work – reinforces to him that things are okay</p> <p>Bragging how he has coped with the impact of his treatment – makes him build self esteem and feel good about himself - trying to capture elements of his past life to build positive perceptions</p> <p>Gold chemo – feels comfort in the thought that he has been given the best of treatment?</p> <p>Suggests he did have side effects from treatment but blaming on the way in which his treatment was administered rather than the impact of the treatment on himself –denial</p>	<p>cannae sit if somebody driving the motor ... irrespective of who it is...I dae it, I, I mean if I was going wi' you, id quite happily go doon the road but I would'nae show you that I wis'nae comfortable, you know, I like driving masel, I love driving, drive, driven aw my days. Driving was my career and my hobby, thousands oh miles a year and I just love driving, so therefore for somebody else to drive me it aint a bloody holiday and every time I've been in the year and a half tae my, I've, I've driven home, I've walked oot that oncology day unit, walked doon the lift, out the front door, stuck the key in the ignition and driven hame, neither up nor down. I've seen me going to my work, I've seen me going for chemo at 11 o'clock and I'm back in my work having a cup oh tea and a biscuit and carrying oan, so that's how much the chemo affected me, it didn't affect me <i>that</i> way and I'm grateful, whether it was the type I was given and they said at the time I was getting it, it was very strong stuff I was getting, you know, because it was gold I was getting ...</p> <p>ROMA Mmm mmm</p> <p>DAN: ... I was getting gold chemo at the time and it was, I think it was £500, was it £500 – no?, £300 – no?, it was ... you know it was, it was away up in the hundreds like, it wis'nae just a wee, it was a bag ... it was either £500 or ... it took an hour, an hour and 20 minutes to ??????? the bag, the bag so that gies you an idea, about an hour and 20 minutes, you're in aboot two hoors the time you get your drip and your, your drip and your God knows ... your flush, your drip and then your flush at the end, your flush at the end, your flush at the ends about 10 minutes like, but em, naw, and I think also em, I think it aw depends who's giving you our chemo, in my mind, because I've had it fae various people and there's always one particular person crops up and the minute I get that particular person [bangs hand on table] ... I have a wee problem ...</p>	<p>Coping and work</p>
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<p>Blaming administration of treatment but then at the same time acknowledging that it could be due the impact of treatment on himself? Trying to convince himself but it's not working</p> <p>Blaming health professionals but then protecting them again</p> <p>Humour</p> <p>Believes in the power of the mind – does he really think that his treatment is working?</p> <p>Recognising that there is a</p>	<p>ROMA Right</p> <p>DAN: ... I've had it twice – a small problem and I'm saying no more ...</p> <p>ROMA OK</p> <p>DAN: burst, it wis'nae the boys fault it burst but the unfortunate thing was he joined it and they might go to another hoose and do the very same, or he's did it twice, it could be a bad, it could just be the way your body was on the day, you could be slightly low, you could have been, you know, so I mean why complain about something, it could be ... the fact there could be 90% yourself and, and the reaction to whatever's been administered to you, it might have ... not a thing to do with the person that's administering it but the only person you can blame is the guy that says look ... or the guy or the lady ... the doctors ...</p> <p>....you've goat tae blame somebody, your no going tae blame yoursel [laughs], so ... that's another, it's psychological at the end of the bloody day, perceived it as psychological ... I don't care... and, and people wi' cancer I think it's ... they're approach. I mean some folk say, you tell somebody and it just goes [demonstrates facial expression of somebody that's just been told that someone has cancer], I don't know why, I can't answer the question, but it just goes eh, and that's you, you're in a psy., a psychological mode eh, it's up to yoursel to get back oot it then ...</p> <p>ROMA Can you tell me a bit more about why you think it's psychological?</p> <p>DAN: Well it must be. As I said to you earlier, your body might be low on that particular day that your getting your, your treatment, irrespective of what treatment I mean eh, as I said to you about that</p>	<p>Humour</p> <p>Reliance on health professionals and treatment to live</p> <p>Positive attitude</p>
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<p>limit to what health professionals can do for him</p> <p>Humour</p> <p>Praising health professionals – protecting them</p> <p>Feels comfort that they are doing their best for him</p> <p>Realises their limitations – does this scare him...then talks about the future...does not want to dwell on the present</p> <p>Knows that his outlook is bad but does not want to think about illness –just look to the future</p> <p>Wanting to go out in caravan but cant – too ill – lost elements of his past life he enjoyed – loss of sense of self</p> <p>Humour when talking about emotive subject</p> <p>Trying to please – scared he is not saying the right thing</p>	<p>earlier, this guy goes to the doctor three days afore it and gets pills and three days later he's still the same, I mean is this guy looking for miracles? I mean they don't all walk on water [laughs], do you know what I mean? So I mean ... and I'm no religious by the way [laughs], but you know, you know where I'm coming fae em, we don't, were no aw God and them that's administering it are no God either, they're there tae dae a joab, they're daing their best, as I've said for an hoor, or well near enough an hoor, they're daing their best, they're no God, but they'll dae their damndest for you, so I mean it's up to you to help as much as you can to assist them, because if you can psychologically and I'm going somewhere where I've never been before, if you can keep your mind oan life and look to well ... the future if you like, you want to be here ... Christ we all want to be here ten years fae now, so I mean why sit on a chair, doom and gloom and say, I've goat this and I've goat that, let's get bloody up and get oan wi' it and that's my, I mean I've goat a new caravan there, I'm wanting, it's sat there for three weeks, I'm champing at the bit,a bloody monument, it's life, you don't, you're no, you cannae turn the clock back, I've said to you earlier, we've goat it, get oan wi' it ... [laughs]</p> <p>ROMA Are you OK to go on talking, I've got another few things to ask you, is that alright</p> <p>DAN: Mmm, aye, am I no very good wi' yae the night hen?</p> <p>ROMA No you're great, you're telling me a lot, honestly, you're telling me lots of, it's all your experiences it's ... it's lovely to hear them</p>	<p>Reliance on health professionals to live</p> <p>Lost activities due to impact of illness and treatment - loss of sense of self</p>
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<p>Neutropenia – lots of symptoms – sense that he was scared as he had not experienced this level of symptoms before – not in</p>	<p>DAN: ???</p> <p>ROMA No, not at all. It's your story I said, that's what's important. You know we were talking there about, we talked about a lot of things but one of the things you were saying, you know you drive the car, you go in for treatment, you come home ...</p> <p>DAN: Aye, aye</p> <p>ROMA ... and last time we were talking you were saying you know that, that Christmas ...</p> <p>DAN: Aye, aye, aye ...</p> <p>ROMA ... when you, you, you said you were sitting by the radiator and you were shivering and you said ...</p> <p>DAN: Oh that was afore I went in for the week</p> <p>ROMA Aye, or when you were in and you said that that was the only time I ever had a <i>real</i> experience</p> <p>DAN: And that was ooooh ... really, that was ...</p> <p>ROMA ... and it was just when you said that was a <i>real</i> experience, can you ...</p> <p>DAN: It was an experience sitting there like a, a budgie in a spor I was sitting there shaking like a budgie on a leaf in a tree because my back was against that radiator, that radiator was fill oan, my back, I was, the wife was sitting here sweating, sitting there and I'm sitting there shaking eh, couldn't get a, couldn't get a heat, just could'nae and, and that was on the Fri., the Friday? And they put it oaf on the Friday and</p>	<p>Symptom</p>
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<p>control of his body – scared</p> <p>Clusters of symptoms during treatment – rigors, sweating, feeling cold</p> <p>Praising health professionals – comfort in that they are caring for him</p> <p>Bad experience for him – talks about eating – significance to him of not losing weight (see previous quote re ‘bean poles’ – associates stigma with this symptom? Also weight loss – underlying fear of death – so prominent to him</p> <p>Praising health professionals</p> <p>Lots of detail about food – important to him that he does not lose weight – symbolic of</p>	<p>we did'nae got tae ... the wife did'nae take us tae em, [name of hospital] to the Saturday and whenever they saw us – you need a bed and I lay in a bed in a ward for a full week fae the Saturday to the Friday and for 24 hours a day, aw that time, I had one needle or two needles in that airm and a bag hinging for a week and you were getting yoan eh, salt tablets, they wee geing me tablets, there were one sister, I admired her, she stood right in front of me and the wife and threw them, threw them oan the flare at the doctor and says – “these do no agree with Mr S”. I was getting, it was a drink, ken the salt drink, I was taking the drink and as quick as I was taking the drink I was sick and the doctor says – “it can't be”, she says “it is”</p> <p>ROMA ??????</p> <p>DAN: ... so she said to him give him the coated tablets and she gave me, she goat me the coated tablets and I had nae problem with them, but they wee geing me this drink and as quick as I was taking it and I'm no joking, as quick as I was drinking it, it was back in the sick bowl. I asked, I had taken it and she says, she just flung it doon oan the trolley, she did'nae throw it on the floor like ... she flung it ... and shoved the trolley – that's no use; cause it ... that's making the patient worse. But for full week oh it was murder and as for hospital food, oh it was like the Ritz, that was the you could'nae get anything bloody decent to eat. You had a cup oh tea in the morning and a roll and Christ you looked, you lay in your bed and looked forward to this roll in the morning and said Christ that'll keep me going an hour now ... I remember it and talked about it on Friday night, talked about it a lot ... this, they were all very, the staff's all very good they just gie oot dinners.. this lassie, she was on the ward, she says eh, got Shepherds Pie the day, so I says I'll have some oh that hen, so she laid it doon and it looked awright, and had a bite at it, I saws I think you've left the Shepherd in it hen, take it away I don't even like it, it was minging, it was rotten but again this is the health board, they're haulin', as I've, well at that particular time they were haulin' meals fae [name of place in England] to [name of hospital]what's</p>	<p>clusters – threat of death nearing</p> <p>Reliance on health professionals to live</p> <p>Weight loss – salient symptom – threat of death/ previous statement re stigma?</p>
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<p>disease progression?</p> <p>Blaming weight loss on food - if he can find a cause, does he feel more in control of this symptom?</p> <p>Humour</p> <p>Angry that he was given food of this standard - prevented him from eating - fear of losing weight? Blaming weight loss on food and not on his illness?</p> <p>Bad experience</p> <p>Lots of medical knowledge</p> <p>Felt violated - not in control of what was happening to him - scared him?</p> <p>Not happy with this ...health professionals having that level of control over him</p>	<p>wrong wi' the old fashioned kitchen?</p> <p>ROMA I know</p> <p>DAN: ... a square meal a day, suppose it's only bloody tatties and mince .. I don't ... it's all frozen, pre-packed Christ, stuffed, stick it on a shelf for three month and say och we'll get it when we need it and that's what's wrang wi' our food the day. Dieticians would be Christ, going mental and they don't know what's, there's stuff in packets through there and what ... OK they tell you that it disnae go off - my arse. You put stuff in a fridge freezer, it disnae go aff, naw it disnae go aff, no..... As long as it's frozen, it's fine - <i>nah</i>. That is the only thing I would say regarding hospital's but as far as experience is concerned, naw I would'nae like tae dae that again, because actually it was because oh the white cells and I, I had two units oh blood to boost my blood when I was in there tae like ken, oh they went to town like, you know they did'nae, there was no there were nane oh, that's a different scenario, no they really went to town wi' it, the service through aw the staff in any department and there was one sister she, she, she bred dogs, and I don't know it must have been like, it must have been something ... it was the needle you goat and eh, it was in your stomach, where I was getting aw this ... and she just came up one day and she just goes like that ... [demonstrates] ?????????? [phone rings] and that was it</p> <p>Chat re phone ringing.....</p> <p>DAN: So eh, and that's how you get the jag, and I came oot black and blue for a couple, I says that was you that did that - aye, I ken .. it was just she just ...</p> <p>ROMA and when she did that, what did you, what were you thinking?</p> <p>DAN: I wasn't thinking nothing, it was too quick</p>	
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<p>Scared at what he saw – did this heighten his fear of death – reality of illness before his eyes</p> <p>Back to praising health professionals again</p> <p>Body – marvellous – using this to cope and convince him that the body can come over many things</p>	<p>beat it, I says very good, if you've beat it, I'll beat it and I agreed wi' the guy... he was in a helluva state and there was another guy up, another guy up in the far away corner, the wife was in visiting me, we were asked to go oot and the guy had just conked oot and died in the bed and 10 minutes later he did it again, so they whipped him oot, he died and they brought him roond twice when we were there, but as I said, the first time we were asked to go oot and then we come, we goat back in ... Christ we were'nae in ten minutes till – away again. He died the guy was sitting up and I'm saying tae masel Christ almighty this is wonder ... I mean, you really get your eyes opened, it's a thing, you never, you go through life up to you know, I went through life and a hospital was the last thing that was ever oan my mind to think about who was in it and what was happening, oh OK, if you need a hospital, you went tae a hospital but em, the things they dae in there, I mean there's two instances in one day that this guy had passed away, they brought him roond and then by the end oh the week he's sitting up quite jovial. They found oot what the problem is like, you know something ... so I mean that to me is a marvel, it's a wonder. Life's a wonder. The body's a ... the body's a marvellous thing, you know ... I mean if you, if you take poison, as long as you don't take too much poison it'll, it'll fight it. Some oh your, some oh your, some your em tablets, as you know, are poisonous and they're feeding them tae yae, like Mickey Mouse sweeties [laughs], you know but it's, it's timed if you like, it's aw set so therefore it's doing the job it's supposed tae dae and your bodies coping with the poison. If you get an infection, what's an infection – a bit of poison, if you get the cold it's maybe no poison, but it's an infection, it comes to the surface doesn't it. The body's ... generating it's ain reaction if you like, you know to keep you ... so therefore that's what was driving me to that radiator, my body was reacting, but the thermostat in my brain wis'nae acting tae the rest oh my body, it was going the other way</p> <p>ROMA I'm interested to know why you described it as that was your, what was it... it was the only time I ever experienced a "real" experience</p>	<p>Social comparison - coping</p> <p>Fear of death</p>
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<p>Real experience, clusters of symptoms, not experienced it before, scared of what would happen – body alien to him - scared he was going to die</p> <p>Shaking, shivering, sweating</p> <p>Could not make sense of what was happening to him at this time</p> <p>Sense that he does not like his wife seeing him this way – tries to protect his family – not be a burden? States in previous interview – wants to hide burden of illness from family</p> <p>Scared – lots of symptoms – never had an experience like this before - scared he was going to die? Could not make sense of what was happening to him at this time –could not find a cause – clusters severe –feels death nearing</p>	<p>DAN: aye</p> <p>ROMA ... ?????????????????????????????????</p> <p>DAN: ... that wis, well I did'nae know what wis wrong wi' me, I wis'nae in control there, I'm sitting there shaking, and really shaking so therefore I don't know, I'm, I'm cold ... I'm cold and the beds bloody soaking. So that's, this is a thing, you know – how am I sweating and I'm sitting here shaking wi' my back against the radiator. Aw my clays were ... in fact ?????????????? was sitting oan my feet ... my legs to stoap me fae shaking, that's how bad I was shaking and your saying to yourself, what a worrying experience this is like, you know, what's causing this? So that's where the experience's coming fae, the wife's sitting here, she's sitting wi' his hands on my legs tae stoap my legs fae going [demonstrates shaking legs], they were rattling aff their ??????????</p> <p>ROMA right</p> <p>DAN: That's the experience</p> <p>ROMA How did that make you feel when all that was going on, what ... ?</p> <p>DAN: Christ I did'nae know what I was feeling, you know, it did'nae, it wis'nae ... you did'nae tend to say, how is this making me feel, it was a case oh what the bloody hell's causing this? And at that time, we did'nae know it was the white cells or the red cells, my white cells were like 1.8 or something. I had no resistance to infection as the report it was put to me; my resistance was zilch and I think it wis, I think my red cells was about 8, my white cells wis about 2 or something so it gies you an idea, that's disnae mean anything to me, but I've a lot of knowledge is dangerous they say.. but I'm learning as I go. I'm, I'm getting more knowledge in as much as I now know the, the level your white cells should be at and the level your red cells should be at,</p>	<p>Symptom clusters – threat of death nearing – real experience</p> <p>Being a burden</p> <p>Symptom clusters – loss of sense of self – body alien to him – not recognizing what was</p>
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<p>Use of 'we'</p> <p>Lots of knowledge of the condition now – does he feel more in control of things if he understands their cause?</p> <p>Building self-esteem – trying to demonstrate positive reflections of self – he has achieved this – feels good that he can help people</p> <p>Learning first aid so that had can help himself more – understand what is happening to him?</p> <p>Had attended first aid course for himself as well as others – to reduce any fear he is</p>	<p>possibly that's because I've just oaf oh a, a First Aid Course through the work there to get my First Aiders Certificate, you go through aw this procedure over a period oh maybe three and half month, you know oor, oor training's quite, we go, we go out to get our training ken, but that is where you, you get they medical books and see when, see when I, Ok I'm getting ?????????? I was getting this em, I was going for this test, there were 10 oh us, you know I'm no bloody interested in First Aid, and for the first couple oh lessons it was boring to a certain extent because it wis away fae the norm, you know, but see as the time passed you goat your heed into the book ...</p> <p>ROMA mmmm....</p> <p>DAN: ... and it does grip yae. And they'll say "what do you do here" – oh you put them in the recovery position, you'll do this and you'll do that and do the next thing and now...I'm no saying I'm a professional, by no means but I'm a damn sight more knowledgeable - ...</p> <p>ROMA You've got a lot of knowledge</p> <p>DAN: ... now, that I did'nae have three month prior, I mean three month prior, if somebody had dropped in the street, id have said, come oan – keep going, you'll no dae it noo, you'll no dae it noo, your, your will would'nae let yae</p> <p>ROMA Mmm, cause you know....</p> <p>DAN: You know and as the, as the, as the guy that was taking it says, they will never believe you for no being able to help somebody, so don't be frightened – a lot oh peoples frightened to go up and say "can I help?" – never be frightened and that was one oh the things he pumped in, if anybody collapses roond aboot yae, never be frightened to go because you'll not be charged wi' anything, you know, you've not administered anything, you've only either sat them up, made them comfortable, put them I the recovery position, sent somebody for an</p>	<p>happening to him</p> <p>Loss of sense of self – build self esteem</p>
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<p>experiencing</p> <p>Lots of medical knowledge – understands why that episode happened now – makes him feel more in control?</p> <p>Building positive perceptions of self – feels good that he can do this – has achieved something</p> <p>Trying to do the right thing – not wanting to disappoint</p>	<p>ambulance, or sent somebody for the medical profession. You know and it's when you get into this kind of thing, you say to yourself, this is bloody marvellous and it does grip you. So I now ... that's where, I now know, well a little knowledge is dangerous but I now know how low your blood should be, how many pints oh bloods in your body, what your temperature, well I know my temperature anyway, but there's aw they kind oh things and when you put them aw the gither, body temperature 36, 36 .. you know, things, things, things ... Christ things normally I would'nae giving a monkey because they were just, I don't know, but ask now, and you'll rhyme them aff, and you will remember them for the rest of your life – I don't know why, in fact we had an incident, we had a guy, the boy that was ?????????????? the two oh them were on the same site and just – ooh, it's since you were here last ... we had a guy he bought a house, he came in at ... came in at 4 o'clock, he took a panic attack – asthma, panic attack and the big fella and I went doon, Ok we'll send out and ambulance eh, but the big fella, big B and I went doon and we comforted the guy and we actually talked, we put him in the recovery position and we talked to him oan his doorstep again.... so we sat and we put a towel doon and eh we sat and put him in the recovery position at the door and we talked to him, by the time the ambulance that guy had ... he wis'nae right ... they took him away in the ambulance – but, he was calm through talking. The two oh us did'nae talk like, we just, I was feeding B and B was feeding me, but between, we did'nae confuse him, you know and we reckon we helped that guy, maybe we did'nae help the guy, we don't know ??..we took the credit of helping the guy...</p> <p>ROMA I'm sure you did, that's, that's ...</p> <p>DAN: ?.....so that's, that's the kinda, that's where the little knowledge is dangerous [laughs]</p> <p>ROMA Oh good, sometimes it can, it can work for you and work against you</p>	<p>Loss of sense of self – (building self esteem)</p>
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<p>Loss of sense of self – life he had in the past is lost-realistic that he will never reach this again – sad – no quality to his life any longer – living is enough?</p> <p>Why point out that it was mentioned by his doctor – is it enough for him just to be alive- does the quality of his really matter to him? Does not want to ask for too much?</p> <p>Emphasises this again –</p>	<p>DAN: Aye, aye ... that's me getting away fae the cancer again by the way</p> <p>ROMA No, no, it's all important, as I say it's all important, I mean I've very conscious that we've gone on here ... just that there's something, if you don't mind can we have a wee chat about this before we sort of finish off ...</p> <p>DAN: aye</p> <p>ROMA ... but when we first started talking, we were just talking about normality and you said to me you says, you know I don't have, you know you said your quality of life that ...</p> <p>DAN: Mmm mmm</p> <p>ROMA ... oh, what was it again ...</p> <p>DAN: Well as Dr R said to me, I would like to give you quality of life, you've got the cancer, but he says we'll do what we can to give you quality of life. Well quality of life to me is what I had before I had the cancer, which I'll never get noo, but you're looking for a s close to that or as damn near it as possible. So the quality of life was never mentioned by me, it was brought up by the consultant who says to me we'll try and give you quality of life, that was after I had the shakes and Christ knows aw what wi' the first lot of chemo cause it was just, and I got the 3rd dose and it was the gold, it must have been too strong for my delicate stomach [laughs]. So eh, he's not, we'll try and give you quality ... I'd like to return quality of life to you if I can, I says thank you very much, so that's where the word "quality of life" came fae, that was not my wording, but that's where it's came fae, so tae me quality oh life is being going oan with your daily business to the best oh your ability with as little pain or suffering as possible is my interpretation of quality of life. That I walk oot there, I walk doon that road there and if I could keep walking I'll keep walking and I'll walk back and I'll no have</p>	<p>Fear of death – value of life</p> <p>Loss of sense of self</p>
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<p>quality of life came from his doctor? Living is enough for him?</p> <p>Contrast to what he said above – work gives him some quality</p> <p>Work a significant coping mechanism for him</p> <p>Building self esteem – almost bragging that he still works – symbolic of him fighting disease and demonstrates to him that things are okay?</p> <p>Feels valued</p> <p>Feel fortunate that he has such a good employer</p> <p>Work gives him some quality of life</p>	<p>any ups or downs, I've had a perfect day. That is what I term quality, but the eh, initial eh, word – quality of life, did not come from me, it came from the consultant who wanted to return quality of life to my way of life</p> <p>ROMA If you don't mind...can you tell me why you feel you don't, you don't have a quality of life, is it from what you've just told me there about?</p> <p>DAN: We have quality of life, we've aw goat quality of life, I mean what you day every day is your life, what I day ever days is my life, I like my work, OK I may be bloody stupid but ... Dr R maintains that my work has kept me going and there's no many firms like the firm that I work wi' that lets yae dae what I'm daing. I mean I'm fortunate to have a company that does that.....I got to my work, if I don't feel it, I was told at the start – if you want to come to your work, come to your work – if you don't feel well in the middle of the day, jump in that motor and go hame</p> <p>ROMA That's great isn't it, that's good</p> <p>DAN: That's a lot ...</p> <p>ROMA Mmm mmm</p> <p>DAN: ... off your mind</p> <p>ROMA Yeah</p> <p>DAN: So that then gives you quality of life, because you are free to suit yourself and I've been told numerous times – you should'nae be here, if you want to be here, we're no sending yae hame, if you don't feel right, you get in that motor and go hame ...</p> <p>ROMA That's good</p>	<p>Work – coping</p> <p>Loss of sense of self – build self esteem?</p>
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<p>Sounds sad that he has no longer any quality of life</p> <p>Hiding the burden of his illness from others</p> <p>Found interview a positive experience – 'it's been good' – not opened up to anyone before?</p>	<p>DAN: ... and don't tell anybody, just go ... [slight pause]</p> <p>ROMA They must think very highly of you eh, to ... ?</p> <p>DAN: They did say that</p> <p>ROMA Yes, yes</p> <p>DAN: Quality of life [slight pause]</p> <p>ROMA Mmm mmm. Are you OK?</p> <p>DAN: Mmm mmm [sounds quite emotional]</p> <p>ROMA ... do you want us to stop here then, yeah ... that, that was really the only thing just cause you were talking about that I thought it would be good to hear what you thought about it, you know how, cause you raised it, so it was just to try and get a wee bit more understanding about it</p> <p>DAN: Was it ... [sniffs]</p> <p>ROMA ... what you thought about it and ...</p> <p>DAN: Mmm</p> <p>ROMA ... that's fair enough</p> <p>DAN: That's the first time I've been like that ... [meaning being upset]</p> <p>ROMA mmmm...</p> <p>DAN: Mmm [still sounds emotional]. It's been good, mmm. Anything else?</p>	
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	<p>ROMA No, that was, you've told me a lot and you've explained a lot that was missing</p> <p>DAN: Sorry about that</p> <p>ROMA There's nothing to be sorry about ... at all ... do you want me, do you want me to switch that off ...</p> <p>DAN: No, carry on</p> <p>ROMA I mean you've, you've told me lots, lots of ...</p> <p>DAN: I don't think so</p> <p>ROMA Oh you have, honestly. I wouldn't say that ...</p> <p>DAN: I don't think you've gained a lot fae me</p> <p>ROMA Oh I have. Your experience is very special and it's really good to hear about it</p>	
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