Understanding distress in people with terminal cancer: the role of the General Practitioner.

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by

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ABSTRACT

Emotional distress is a common problem which people present to their General Practitioner (GP), yet the evidence base for dealing with it remains uncertain. This thesis looks specifically at the role of the GP in managing emotional distress in people with terminal cancer. It examines need from two distinct theoretical perspectives. The aim was to add breadth and depth to clinical understanding of distress, whilst also offering insights into knowledge in evidence-based practice.

A biomedical, pathological account views distress as potentially indicative of an underlying mental illness such as depression. Palliative care research has identified depression as a common, treatable cause of distress in people with terminal cancer, but little is known about the burden of disease in primary care. I therefore started with a depression prevalence survey in a sample of 70 patients with terminal cancer identified from General Practice lists. I identified a lower prevalence of depression in these patients (4.1%, 95% CI 0-8.8%) than would be predicted from palliative care studies. A critical review of the literature sought to explain the discrepancy between my study and previous published work. This identified theoretical and methodological problems with the diagnosis of, and hence research into, depression.

My second perspective was a qualitative study of lived experiences of distress, drawing on Bury's descriptions of illness as a cause of Biographical Disruption. Semi-structured interviews were conducted with a purposive sample of 19 patients with terminal cancer. Analysis revealed that life events, including terminal cancer, threatened an individual's core-self – defined as what mattered most to them. Threats caused emotional disturbance. In some cases, physical and emotional exhaustion contributed to Biographical Disruption. More commonly, the effects of threats were managed through a combination of emotional and narrative support. In the thesis, I present a model of Self-Integrity to explain the findings, and discuss the implications for health care. I discuss how interactions with health care services and professionals may support or disrupt the process of maintaining the core-self and Self-Integrity.

To conclude, I undertake a critical examination of both studies and the whole thesis. I seek to describe the implications for understanding knowledge and practice. I propose that integration of the two studies offers new insights which may be of benefit in clinical care. However I identify the need to broaden the notion of what is considered 'legitimate' evidence in clinical practice if these benefits are to be achieved.

LIST OF FIGURES

ABBREVIATIONS

CIS-r	Clinical Interview Schedule (revised)
DSM	Diagnostic and Statistical Manual of mental disorders
EBM	Evidence Based Medicine
EBP	Evidence Based Practice
EDS	Edinburgh Depression Scale
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
ICD	International Classification of Disease
IMD	Index of Multiple Deprivation
MMSE	Mini Mental State Examination
PPV	Positive Predictive Value
SADS	Schedule for Affective Disorders and Schizophrenia
SCID	Structured Clinical Interview schedule for DSM
WTE	Whole Time Equivalent

DECLARATION

This thesis is the result of my own work. The material contained in the thesis has not been presented, nor is currently being presented, either wholly or in part for any other degree or qualification.

The field-work was carried out in Liverpool. I was solely responsible for all data collection and analysis.

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The Silver Swan

"The silver swan, who living had no note,

When death approached unlocked her silent throat;

Leaning her breast against the reedy shore,

Thus sung her first and last, and sung no more:

Farewell, all joys; oh death come close mine eyes;

More geese than swans now live, more fools than wise."

(attributed to Orlando Gibbons 1583-1625)

(In: Ledger P. (1978) The Oxford Book of English Madrigals. Oxford: Oxford University Press.)

Chapter One: Knowledge and practice

This is a thesis about General Practice and about being a General Practitioner (GP). It describes my attempts to develop further my understanding of my role as a GP in supporting patients, focusing particularly on those with emotional distress. But it is also about knowledge and practice. Knowledge informs clinical practice; but what we know depends on where, and how, we look.

The search for a knowledge base which adequately meets the demands of my experiences of health, health care and clinical practice has shaped my career to date. I have worked in hospital medicine, Public Health and Primary Care; I have tried laboratory research, community project evaluation and patient-centred research. The next step was this thesis.

1.1 Knowledge in Clinical Practice

The range of knowledge available to inform my clinical practice is diverse: from the apparent 'certain fact' of undergraduate lectures and text books to the uncertain complexity of clinical experience. Professionally driven critical questioning of evidence sits alongside personal reflections; the latter based on the beliefs I hold, derived from social, familial, and cultural norms, together with lived experiences. My experiences as a patient (most notably a patient diagnosed with a brain tumour at the age of eighteen) vie with my experiences as a clinician, 'scientist' and researcher. The question of how I can and should legitimately draw on each of those has underpinned much of the reflections shaping my first years in clinical practice.

Robinson and Heywood (2000) argued that GPs use different types of knowledge within a consultation in order to meet their patients' needs. They proposed that newly qualified doctors rely more on what they call 'deliberative knowledge': drawing on the range of 'facts' acquired through training to diagnose and treat patients. However, with time, doctors make greater use of 'intuitive knowledge' or experiential knowledge to make clinical decisions for individual patients.

However, the need to ensure clinical practice remains up-to-date with advances in medical research (Sackett et al. 1996), together with a demand for greater accountability in the delivery of high quality, cost-effective health care (Jones & Higgs 2000), have contributed to the current emphasis on promoting Evidence Based Medicine (EBM). EBM requires "the conscientious, explicit and judicious application of the current best evidence in making decisions about the care of individual patients" (Sackett et al. 1996: 71). Crombie (1997) proposed that the current emphasis on evidence-based practice represents a fundamental shift in the nature of clinical practice from decision-making based on practitioner expertise (intuitive knowledge), to an emphasis on knowledge from scientific research (deliberative knowledge). Sackett et al. (1996) however argued that experiential knowledge is still needed in EBM, not least to determine the applicability of research evidence to individual health experiences.

Evidence-based practice (EBP) has been welcomed for its emphasis on the explicit use of "credible evidence, sound reasoning and defensible professional judgement" (Jones & Higgs 2000: 308). However, some critics have argued that EBP focuses on scientific evidence of disease, over and above the lived experience of patients. Human experience of health and illness is more than the biology of pathology (Davey 1994, Scambler 1997); evidence-based practice has been accused of dehumanising clinical care through devaluing knowledge of human experience in favour of scientific knowledge of pathology and disease (Mykhalovskiy & Weir 2004). Effective clinical practice requires a knowledge base which can accommodate and explain the breadth of health experiences (Jones & Higgs 2000).

The difficulties in applying the principles of EBM to clinical practice lie in deciding what counts as "credible evidence" (Jones & Higgs 2000: 308); and how we understand the process of the "judicious use" of knowledge (Sackett et al. 1996: 71), and therefore "defensible judgement" (Jones & Higgs, op cit). Sackett et al. (op cit) emphasised scientific knowledge as the mainstay of legitimate evidence: experimental evidence (such as the Randomised Controlled Trial) for understanding therapeutic effects, and epidemiological studies for understanding diagnosis and prognosis. Clinical experience should be used to determine how the scientific knowledge can be applied to the problems of an individual patient.

Yet there is a growing evidence base highlighting the contribution that 'lay knowledge' can make to improving the medical evidence base. Rogers & Pilgrim (1997) explored lay experiences of mental illness, demonstrating differences in professional and lay accounts of the nature and causes of mental illness. However, in doing so, they identified potential new approaches to mental health care including a range of health promotion activities. Their work supports the position of Caron-Flinterman et al. (2005) that knowledge from patient experience can inform and positively improve biomedical research/knowledge, contributing to knowledge on health needs, aetiology, therapeutic approaches and priorities in health care and research.

Although user involvement in the development of research and health care is now a stated priority (Farrell 2004), in practice there is still a greater emphasis on a scientific account of disease in health policy and practice. These discrepancies arise because scientific knowledge is valued more highly than other forms, by virtue of its defined appeal to objectivity and 'truth' (Potter 2000). Within the EBM movement, Sackett et al. (1996) argued that non-experimental evidence of therapeutic effect may be biased and should be avoided. Lay knowledge is viewed as subjective and unreliable. Thus within medical practice, a single methodology for knowledge production to inform clinical decision-making is valued over all others. We have a 'hierarchy of knowledge' (Guyatt et al. 1995) within health and health care, where personal (including lay) accounts are far down in the list of priorities.

However, the assumption that scientific knowledge is 'better' than other forms is based on a set of assumptions about the nature of knowledge: the assumptions of scientific realism (Potter 2000). Scientific realism states that scientific practices are the best ways to produce knowledge of the 'real' world which exists external to our perceptions of it (Potter 2000). Scientific method purports to offer certainty and objectivity, both of which are used to justify its dominance within the hierarchy of knowledge informing medical practice and policy. This assumption - that scientific method offers the 'best knowledge' - is so prevalent within modern western health care that it often goes uncontested (Seale & Pattison 1994). Yet it has been contested by those who theorise on, or study, the question of knowledge.

1.2 The nature of knowledge

Modern debates about the quality of knowledge (or 'evidence') for health policy and practice focus on the method of knowledge production, valuing scientific method above all others (Davey 1994, Muir Gray 1997). The debate is primarily an epistemological concern (how we know about the world) rather than an ontological one about the nature of the 'reality' which that knowledge describes (Okasha 2002), since 'truth' is a largely uncontested concept (Davey 1994). However building on the work of Mannheim, sociologists of knowledge have studied the construction of knowledge within societies (Dant 1991). They argue that all knowledge is constructed, being shaped by societal forces and so reflecting the value systems of the dominant group rather than representing a certain or absolute 'truth' (Berger & Luckmann 1966, Dant 1991). The rules that distinguish 'genuine knowledge' from 'mere thought' reflect value structures, and hence power structures, within a given society (Dant 1991). Thus from the perspective of the sociology of knowledge, 'reality' or 'truth' (as well as knowledge about that reality) is a socially constructed concept (ibid). Truth is constructed to fit different belief systems. This opens up to question an absolutist stance whereby scientific practice is said to offer knowledge of 'certain truth' (Davey 1994, Okasha 2002).

This critical account of knowledge has been used to explore the nature of medical knowledge (White 1991). Assumptions that the scientific knowledge which underpins medicine is "homogeneous, culture-independent and founded on objective observation and experimentation" (Lowy 1988: 134), representing value-free statements of truth, are questioned by this critique. Lowy argued that the scientists who purport to discover objective truth are trained to think and "see reality" within their given "thought-style" (Lowy 1988: 135). They create theories and test them experimentally, but all within the constraints (assumptions) of an assumed model of the world. These models within which they explore the world are influenced by religious, economic, political and other social factors. All knowledge is therefore knowledge from a certain perspective: knowledge is not discovered but socially structured and created (White 1991). Medical 'facts' are therefore seen as a socially constructed view of reality rather than the 'objective labels' for 'real' natural phenomena which they purport to be (White 1991). Viewing medical knowledge from the perspective of the sociology of knowledge questions the dominance of biomedical or scientific accounts (or 'knowledge') of illness which dominate current policy.

Other models of health outside of western biomedical knowledge exist (Dant 1991, Seale & Pattison 1994), although they are also dependent on the theoretical perspective which created them. The critical stance offered by the sociology of knowledge questions the current approach whereby competing models of knowledge for medical practice are judged through an appeal to a status of truth. However, it does not provide an alternative approach for understanding and using knowledge. The purpose of knowledge within social settings must be considered. Knowledge is important for social functioning (Lee & Newby 1987) binding societies together to integrate a social group and enhance its functioning (Dant 1991). In 'The Birth of the Clinic', Foucault (1973) argued that modern medicine as a whole is the product of a managed society, and necessary for social functioning. Thus to undermine the value of a knowledge base without providing an adequate alternative leaves individual practitioners and their patients uncertain, but also threatens broader social structures which depend on the use of this knowledge. The question therefore arises how should we be using knowledge in clinical practice?

1.3 Critical use of knowledge in clinical practice

Like Seale & Pattison (1994) and Jones & Higgs (2000), I believe that experimental science focusing on disease pathology, even when tempered by professional experience, cannot provide the integrated knowledge base needed to meet the range of demands of clinical practice, which includes the human experience of disease. I believe that the "judicious application of best evidence" (Sackett et al. 1996: 71) must include the critical use of the highest quality knowledge of the human experiences of health and illness, as well as pathology. Medical knowledge (if defined as scientific knowledge of pathology) is inadequate to meet the needs of medical practice.

My concerns about the discrepancies between scientific medical knowledge and medical practice are not new. Almost ten years ago, Mathers & Rowland (1997: 177) argued that an epistemological stance favouring only scientific knowledge had "very limited application in our day-to-day work [as GPs, and]...can create very real difficulties for both doctors and students as they struggle to apply such a model that does not very often or necessarily fit". They proposed that a postmodern approach to evidence and knowledge better reflects the "real" world of general practice (ibid: 177). Postmodernism describes a collection of theoretical perspectives which openly accept the inevitability of uncertainty, and recognise that knowledge is the product of the method which produced it, rather than "an objective reality" (ibid: 178). Mathers & Rowland (1997) therefore proposed that a critical reflective approach to knowledge in clinical practice and training within General Practice is required.

If truth, like knowledge, is constructed to fit various belief systems and is an uncertain concept, using truth as the primary indicator of the quality of knowledge for clinical practice becomes problematic. However if we remove 'truth' as the criterion by which to assess knowledge, then what criterion or criteria should be used to judge between competing knowledge bases? Mannheim (1952) argued that we all judge between different sets of knowledge as a necessary part of social functioning: identifying what we believe and don't believe to be 'true' based on social and cultural values and norms. The problem in clinical practice is that we need to make that process explicit. We need an alternative method by which to judge between competing knowledge claims.

In this thesis, I therefore adopt the subtle realist approach proposed by Hammersley (2002). Subtle realism puts to one side the question of whether there is or isn't an external reality; since, it argues, even if there is, we can never know it with certainty. We therefore need alternative criteria for judging between competing knowledge claims than that of 'truth'. Attention is shifted to the need for a reflexive review of the whole research process underpinning knowledge construction, including theoretical, epistemological and ontological assumptions (Doucet & Mauthner 2002).

Maxwell (2002) identified five criteria for judging the merits of the knowledge generated from research within a subtle realist perspective. Research should be assessed for its descriptive validity: an accurate recording of what happened; and its interpretive validity: how accurately the interpretations reflect the individuals' perspectives. Theoretical validity questions how well the account serves as an interpretation and explanation of the phenomenon, whilst generalisability looks at the ability to infer from the account. Finally evaluative validity looks at the use to which the knowledge produced from the research process can be put. A subtle realist approach views the processes and assumptions underpinning knowledge production, together with its utility, as fundamental to judging between knowledge bases. This is in contrast to the single reference point - that of 'truth' - used in the realist stance underpinning biomedical scientific approaches (Davey 1994).

Good clinical practice requires that I continue to explore and challenge the knowledge I use in order to understand and treat the illness experiences which patients bring to me. As Jones & Higgs (2000: 313) state, "understanding the nature and credibility of knowledge and evidence is the first part of the application of evidence to practice". Traditional teaching of EBM perhaps focuses on the 'credibility', albeit within a narrow focus of scientific method. This thesis aims to take a critical stance on understanding the nature of knowledge and evidence, in order to contribute to a better understanding of how it may be applied to clinical practice.

In this thesis, I am going to look specifically at a common problem seen in clinical practice: that of emotional distress. I will critically compare two potential sources of knowledge that I may use in my clinical practice: a biomedical account of the assessment of need, and a lay perspective of health experience and distress. I will consider both under the umbrella of a subtle realist approach to questions of ontology and epistemology. By comparing and contrasting the two knowledge bases, I hope ultimately to comment on the management of distress in primary care, but also on the use of knowledge in clinical practice.

Chapter Two: Considering emotional distress

In this thesis, I intend to critically explore the knowledge available to inform my clinical practice. In particular, I have chosen to look at the question of managing emotional distress in primary care: because it is a common problem, but also one where the knowledge base remains unclear. I begin this chapter with a consideration of the current literature on emotional distress in primary care in order to describe the development of my research question and subsequent study.

2.1 Considering emotional distress

It has been estimated that 30-80% of GP consultations result from psychosocial problems (del Piccolo et al. 1998), and are commonly associated with emotional distress (Ormel et al. 1990). Emotional distress may also complicate physical illness, and may indeed worsen the impact of that illness (Brouwer et al. 2005, Nash et al. 2006). Emotional distress can threaten physical health, for example through an association with increased risk taking behaviour (Sterk et al. 2006, Tschann et al. 2005). It has been demonstrated that emotional distress influences health service use (Callahan et al. 1998, Frostholm et al. 2005); contact with health services may also cause emotional distress (Ukpong & Owolabi 2006). Estimates of the burden of psychological distress in primary care patients lie between 17-23% (Callahan et al. 1998, Goldberg & Huxley 1992, Pini et al. 1995); and for many people, their distress is the primary reason for their consultation with their GP (Callahan et al. 1998, Pini et al. 1995).

Despite the identified burden for patients and health services alike, there is still much uncertainty surrounding the conception and treatment of distress. Biomedical research often uses the terms psychological and emotional distress interchangeably (for example, see Callahan et al. 1998, del Piccolo et al. 1998, Pini et al. 1995); since significant emotional distress is regarded as indicative of an underlying pathological state, the commonest being anxiety or depression (Brody et al. 1997, del Piccolo et al. 1998). Yet a psychologically defined assessment of need related to emotional distress does not necessarily describe the totality of the need identified by patients. For example, Brody (1997) reported a study in which patients attending primary care practices were asked directly "how much effect has emotional distress had on the way you have been feeling and functioning?" Of 403 patients in the study, 60% reported that emotional distress was having some effect (42%) or a great deal of effect (18%) on their feeling and function. 63% felt it was "somewhat" or "extremely" important that their GP try to help them with their distress. However, only 17% of people met the criteria for a diagnosis of a psychological disorder (either major or minor depression). So although distress was a significant health problem for 60% of the study sample, current biomedical (psycho-pathological) understanding of distress could provide an explanation for only around one third of those patients.

Reviewing Brody's (1997) findings, Gallo (1997) argued that we need a new system for classifying mental distress in primary care patients, since current pathological models of depression cannot explain the range of self-identified need. Alternatively, perhaps GPs should only treat people with distress which can be explained by existing pathological models: using professional knowledge rather than 'subjective (lay) experience' to define (health services related) need. However, it is acknowledged that the pathological model of mental illness is still underdeveloped (Pilgrim & Bentall 1999), certainly in comparison with our understanding of mechanisms in many 'physical' disease states. With time, we may improve our understanding of the pathological mechanisms behind distress symptoms and hence develop a new or extended classification of mental illness which offers a better explanation of the range of experiences of primary care patients. Yet patients request help now, despite the uncertainties in our current knowledge base.

Gallo (1997) proposed that any new system for defining need should incorporate patients' own assessment of the impact of perceived illness on functioning. Need is therefore defined by the impact of illness on an individual's life, especially their ability to function, rather than purely on the basis of pathological change. Following Gallo's (1997) approach would mean that experiences of distress which cannot be explained by current pathological models of mental illness would still be a legitimate target for primary care intervention. Knowledge informing clinical practice would therefore need to draw equally on medical, scientific and lay accounts; bringing together an objective scientific world and a subjective lived world. This could meet the demands of evidence-based practice as outlined in Chapter 1, so long as we develop mechanisms to support the "judicious use" of both forms of knowledge (Sackett et al. 1996: 71), recognising the strengths and limitations of both.

2.2 Developing the research question

I wanted to explore the strengths and limitations of both biomedical (pathological) and lay accounts of need with reference to understanding emotional distress. I opted to focus on accounts of emotional distress in a particular patient group: those with a terminal diagnosis of cancer. Questions of what may be seen as 'normal' or 'appropriate' distress (as opposed to something pathological) are even less clearly defined in this patient group then in those without concomitant physical illness (see section 4.5.1, p63). I would argue that terminal illness is an example of what Giddens (1979: 123) described as a "critical situation": a chance to observe the social world in a setting in which it is "radically disturbed", examination of which may help us better understand the everyday world. I therefore identified my research question as: how should GPs manage emotional distress in people with terminal cancer?

2.3 Reviewing the existing literature

I began by reviewing the existing research literature on emotional distress as described from two theoretical perspectives: a pathological (biomedical) account; and a sociological account offering an insight into individual lived experiences as an alternative to the biomedical, professional understanding of distress.

2.3.1 *Biomedical explanations of emotional distress*

Modern biomedical accounts of mental illness are underpinned by a scientific model of disease, whereby symptoms are viewed as the result of an underlying pathological process (Goodwin & Ghaemi 2000). Interpretation of patient symptoms leads to diagnosis of the underlying pathology, and hence access to treatment and prognostic information. However, pathological mechanisms for mental illness are not well described; classifications of mental illness have been developed which assume (but cannot prove) underlying pathology (Dilling 2000). Kraeplin was the first to describe such a system of classification (ibid); and his work forms the basis for the current system of classification in Europe – the World Health Organisation International Classification of Disease, currently in its 10th edition (World Health Organisation 1992). Clinical diagnoses of mental illness therefore reflect what clinicians believe the underlying disorder to be (Andrews et al. 1999), rather than being a certain statement about the underlying pathology: they are "names for theories rather than names for things" (Wing 1978). Despite current uncertainty over the validity, or certainty, of the concepts it describes, a pathological model of mental illness persists because of its clinical utility: its ability to predict outcomes and response to treatments (Becker 1974, Kendell & Jablensky 2003).

Within a biomedical model, patients subjective accounts of emotional distress are interpreted by health professionals to reveal (or refute) the existence of an underlying pathology or mental illness. The commonest mental health problems seen in primary care are depression and anxiety (Linzer et al. 1996); and of these, depression is the most extensively researched within people with terminal cancer. In this thesis I will therefore focus on a biomedical account of depression in understanding emotional distress in people with terminal cancer.

Studies have estimated that between 1% and 69% of patients with terminal cancer suffer from clinical depression (Bowers & Boyle 2003, Hotopf et al. 2002, Payne 1998, Potash & Breitbart 2002, Stiefel et al. 2001, Wilson et al. 2000). Rates of depression are, on average, higher than those reported in the general UK population (2.1% in a large study by Meltzer et al. 1995). However, it is argued that clinical depression can be differentiated from what might be described as 'normal sadness' when facing terminal illness (Chochinov 2001, Hotopf et al. 2002, Werth, et al. 2002): depression is not an inevitable part of dying. Terminally ill patients presenting with emotional distress (for example, upset, anger, fear, despair) *may* therefore have an underlying disease, namely depression.

Untreated depression in the terminally ill is associated with reduced quality of life for patients and their carers (Alexander et al. 1993, Lloyd-Williams 2002); increased difficulty in palliation of physical symptoms such as pain (Lloyd-Williams & Payne 2003); and from a health services perspective, longer inpatient episodes and elevated health care costs (Bowers & Boyle 2003). Antidepressant medication can improve symptoms of depression (Golden et al. 1991, Ly et al. 2002, Maguire 2000, Stiefel et al. 2001), even in the final days and weeks or life (Lloyd-Williams 2003).

In reviewing the existing studies, the European Association for Palliative Care Expert Working Group on Depression argued that under-detection and under-treatment of depression in palliative care was a major problem, significantly threatening the quality of life of patients and their families (Stiefel et al. 2001). They advised that health care professionals should adopt an active stance - screening for depression and undertaking a trial of treatment, rather than taking a 'wait and see' approach. They recommended that in those identified as having depression, antidepressants should be used without delay - opting for amphetamines or neuroleptics in patients with a very limited survival time.

2.3.2 *Sociological accounts of distress: critiquing the validity of a medical model of depression*

Pathological models of depression assume that the illness experienced by patients is evidence of an underlying disease, and hence can be explained by a biomedical model of illness (Goodwin & Ghaemi 2000, Seale & Pattison 1994). The biomedical model assumes that illness results from an identifiable cause, and can be treated and (often) cured by addressing the root cause (Seale & Pattison 1994). The underlying disease is a 'real' phenomenon; it exists as something external to our experience or understanding of it (Pilgrim & Bentall 1999). However, social theorists have argued that medical knowledge is only one way to understand health and illness; others include a patient-centred model which emphasises patients' experiences over causal theories, or a social model of illness which locates the cause of illness at the level of societal structures rather than a 'fault' in the individual (Seale & Pattison 1994). Identification of distress as a mental illness has been critiqued as representing medicalisation of normal human experience in order to extend the power of medicine, and as a form of social control of undesirable behaviour (Shaw & Woodward 2004). Dowrick (2004: 95) identified commercial, professional and cultural "drivers" for describing lived experiences of distress or suffering as a "diagnosis" of depression. These approaches question the medical model's status as the 'best way' to understand human experience, pointing to phenomena which question the objectivity or universality, and therefore the validity, of the notion of depression.

Social constructionists argue that depression is not a 'real' phenomenon but a concept constructed by societal groups/processes to explain human experiences of distress (Senior & Viveash 1998). A classical example of this perspective is described in the work of Rosenhan (1973). In his study, eight healthy people faked symptoms of hallucinations so as to be admitted to a psychiatric unit. Following admission, they ended their complaints of hallucinations and behaved as normal, recording observations of their experiences of being an inpatient. Subsequent analysis of their medical records revealed that normal everyday behaviour had been reinterpreted as pathological. For example, their record-keeping was documented as evidence of pathology (obsessive note taking). Rosenhan (1973: 258) proposed that "the hospital environment is a special environment in which the meaning of behaviour can be easily misunderstood". Interestingly, although professional staff were unable to identify the 'fakes', patients were often able to do so. This may suggest there is something 'real' or shared amongst those with psychotic illness that they recognise as absent in others.

Rosenhan's (1973) study may have simply revealed poor diagnostic standards in the participating psychiatric units. Alternatively, it may present empirical evidence for the social constructionist argument: that mental illness and depression are culturally constructed concepts with behaviour interpreted as 'normal' or otherwise according to a set of socially derived criteria. The latter perspective is supported by cross-cultural social and linguistic studies which identify that various societal groups conceptualise the phenomena of distress, emotions and depression differently.

One example comes from a study of depressive experiences in Latvia. The recent political changes in Eastern Europe have led to significant and rapid cultural shifts with previously 'closed' communities being rapidly flooded with western cultural ideas. Skultans (2003) investigated the effect on local understanding of mental health problems. Prior to the political upheaval, emotional or mental distress (referred to locally as *nervi*) was collectively understood as the result of living under the communist regime. However, following independence, people started to describe experiences of distress as a personal illness or disease, rather than the collective *nervi*. Where people previously understood their distress as reflecting problems of the state, they now saw the problem as their own: being unable to "cope with myself'. Professional understanding also changed; moving from an understanding of a collective emotional experience of repression to an individual pathological state.

Similarly, Wierzbicka's (1999) linguistic analysis identified cultural differences in whether emotional distress is regarded as pathological. She identified that only cultures underpinned by Anglo-academic psychology viewed composure, or absence of emotional upset, as 'the normal state'. Italian, German and Russian languages, for example, do not reflect the same beliefs. These languages have no equivalent word for the English 'upset', with its assumption of distress as a deviant state away from a 'normal' state position of equilibrium. Indeed some cultures view the absence of emotion as an abnormal state: a "deadening of the heart/soul" (Wierzbicka 1999:17). Linguistic studies also demonstrate that the concept of depression is not universal, again raising questions about the validity of the concept. There is no word for depression in the German, Russian or Samoan languages (ibid). Some Asian cultures have no equivalent to the medical description of unhappiness as depression (Fenton & Sadiq-Sangster 1996).

In seeking to distinguish whether depression is cultural or biological, Huang & Mathers (2001) undertook a comparison of postnatal depression in the UK and Taiwan. They found that the prevalence of depression was similar in both communities, despite significant cultural differences. They therefore acknowledged the influence of cultural factors on the expression, causation and understanding of depression, but argued that the prevalence estimates suggested the presence of at least some (shared) biological determinants. Thus perhaps there is a 'true' pathological state of depression, but its expression (by patients) and detection (by doctors) is subject to cultural and societal forces.

Supporters of a biomedical approach (who therefore believe in the 'truth' of mental illness) would state that Skultans' work (2003) describes a learning process. Exposure to western ideas has helped develop Latvian thinking from the 'out-dated' belief models (that mirror some of those seen in earlier, and 'less sophisticated', western societies) to embrace modern scientific (and 'correct') understanding of the concepts. Similar explanations are offered to account for observations of Asian communities which have no conception of depression (Karasz 2005). For example, in some parts of the Indian subcontinent, people describe sadness as a 'fallen' or 'painful' heart (Kleinman 1980). Rather than this being seen as evidence for the social construction of concepts of depression (and therefore its non-existence in some cultures), western psychology proposed that people in such communities are unable to express emotional distress in psychological terms. People use physical descriptions to convey emotional distress; a western psychiatric interpretation would be that the person is 'really' depressed, but expressing their suffering through culturally acceptable mechanisms of pain. This so-called somatisation hypothesis has been offered to explain the experiences of communities which 'lack understanding' of depression and therefore express its symptoms in other ways (Karasz 2005).

However medicalisation critiques described, for example, by Dowick (2004) or Shaw and Woodward (2004) argue that whilst unhappiness is part of human existence, it is no longer tolerated. What was once a human emotion and lived experience has become a diagnostic criterion; the problem is perhaps a societal one, not a medical one. Traditional social mechanisms for supporting unhappiness (the family, neighbourhood, or church) have declined, so medicine has taken their place. Critics of a medicalisation hypothesis highlight that, to date, it has failed to offer an adequate alternative solution to addressing the needs of distressed people (Pilgrim & Bentall 1999). Yet Dowrick (2004), amongst others, has identified a framework within which to understand and address distress. The limitations of these alternative perspectives arguably stem from their current restricted ability to challenge the dominance of the biomedical perspective on mental illness.

2.3.3 *Looking at emotions*

An alternative approach has been to focus on understanding the nature of emotions as a concept in their own right; looking at the societal structures and forces which are part of understanding the phenomena. Turner & Stets (2005:10) described emotions as a "motivating force" which enables people to respond to situations. Anger, happiness and fright, amongst others, "energise responses" (ibid: 11); both prompting people to respond to situations and also directing their actions. Whilst depressive symptoms are commonly described in pathological frameworks as associated with lethargy and inability to function, Gut (1989: 11) argued that the emotional experiences which constitute depression may still be seen as "productive". Productive depression may be viewed as an appropriate and functional reaction to conflict or stress; leading to social withdrawal, and hence facilitating the healing process necessary to "arrive at a better grasp of the difficulty to which we are responding and what can be done about it" (ibid: 17). Lyon (1996) similarly argued that depression can be viewed as an appropriate response to environmental stressors, which prompts individuals to withdraw in order to deal with the threat or upset.

A number of accounts of emotions focus on the link between emotions and the self. For example, Williams & Bendelow (1996) argued that emotions form the basis for our lived experience of our bodies in health and illness, and also a sense of a shared experience with others in our social group. They proposed that an "active emotionally expressive body is the basis for the self, sociality, meaning and order" (ibid: 37). So perhaps an alterative view of Skultans' (2003) study could argue that distress or *nervi* had a function in creating a shared or collective sense of being, contributing to personal meaning and a sense of community.

2.3.4 *Is depression real or a construct of our culture, and does it matter?*

The question arises whether depression, and indeed mental illness, is something 'real': an unchanging phenomenon which exists independent of our view of it (Pilgrim & Bentall 1999). Alternatively it may be a 'social construct': an idea created by societal structures and forces to explain our experiences, but which does not exist outside of our understanding of it. Or perhaps it is both: depression exists as a 'real' pathological state, but it is our attempts to know about that state which are socially constructed. As Pilgrim & Bentall (1999) said, the problem is an epistemological problem (how we know about reality) rather than an ontological one (what that reality is).

In this study I looked at what I suggest is a single phenomenon (the lived experience of emotional distress in people with terminal cancer) through two theoretical 'lenses': a biomedical pathological account, and an existential account focusing on lived experience. I judged the findings from the position of a subtle realist ontological stance. The two perspectives offer an opportunity for theoretical triangulation: adding to the strength and utility of my findings through a comparison of the two views as well as the individual contribution from each. However, my aim is not to judge which is 'real', since subtle realism does not use truth to judge between knowledge. Instead I hope to assess the strengths and limitations of both knowledge bases in supporting my clinical practice and the care of people with terminal cancer who are experiencing distress.

2.4 Aims & Objectives

I therefore explored my research question "how should GPs manage emotional distress in people with terminal cancer?" from two theoretical perspectives: a pathological account and an existential (phenomenological) account. I identified the following set of aims and objectives.

AIMS:

- To critically explore the contribution of a medical theoretical account of emotional distress to medical practice: through a consideration of palliative care guidance on depression in patients with terminal cancer;
- To critically explore the contribution of lay knowledge on emotional distress to medical practice: through an investigation of the impact and meaning of emotional distress for individuals with advanced cancer, together with their experiences of dealing with the problems;
- To identify areas of overlap and discordance between expert and individual assessments of experience and need in order to comment on questions of knowledge and clinical practice.

OBJECTIVES:

- To identify a representative sample of people with advanced metastatic cancer from GP practices in Liverpool;
- To undertake a two-stage community prevalence survey of depression in this group, and critically review the results in light of the existing literature;
- To identify a purposive sample from that group for a qualitative study exploring the impact and meaning of emotional distress;

- To identify an appropriate methodology to explore issues of distress in this sample, and thus undertake the study;
- To critically review both arms of the study to identify lessons for practice and policy.

2.5 Outlining the thesis

In Chapter 3, I take as my starting point the current best practice recommendations coming out of the medical palliative care literature. Evidence-based practice stresses the need to screen for depression as a common but treatable cause of distress in people with advanced cancer (Stiefel et al. 2001). I therefore began my research by assessing the prevalence of depression in primary care patients with terminal cancer in order to see if the burden of need was as described in the literature.

In Chapter 4, I critically review the results of my survey in light of previous studies in order to seek to explain observed differences and hence to comment on the utility of a medical account of depression in understanding patient needs. I conclude by appraising the contribution of medical theory to understanding distress.

In Chapters 5-9, I outline the methodology, results and critical analysis of my qualitative study seeking to understand lived experiences' of emotional distress. I explore the strengths and weaknesses of this alternative perspective for understanding individual patient need and clinical practice.

In chapter 10, I review the totality of the work with reference to my identified questions. I consider the implications for clinical practice and hence highlight suggestions for taking this research forward in the future.

Chapter Three: Evidence-based General Practice - applying knowledge from palliative care to primary care practice

3.1 Outline of the Chapter

Chapters 3 and 4 address my first aim: namely, to critically explore the contribution of a biomedical theoretical account of emotional distress to medical practice. In this chapter, I will describe my study to investigate whether findings from the biomedical palliative care research described in Chapter 2 (p10-12) can be extrapolated into a primary care setting.

3.2 Palliative care research in primary care practice

Chapter 2 outlined the findings from palliative care research which highlight the prevalence of depression in people with terminal cancer, and advocate a proactive approach to identifying and treating depression. However, it cannot be assumed that the guidance coming out of a palliative care setting can be directly applied to primary care. It is possible that the burden of depression in primary care populations with terminal cancer is even higher than that identified in the existing literature. Palliative care services may prevent depression through offering supportive environments and intensive management of symptom control; in primary care where such support is absent, depression rates would therefore be higher. However, it may be that only people at high risk of problems, including depression, get referred into palliative care settings. The actual prevalence of depression in the primary care population with terminal cancer may be much lower.

This has important implications for clinical practice. Diagnosis of depression requires an assessment of presented symptoms (and signs) to determine the likelihood that there is an underlying pathology. The diagnostic 'test' in the case of depression, and indeed all mental illness, is the clinical interview. Yet the probability that a person with a positive diagnostic test truly has the underlying disease (the Positive Predictive Value of a diagnostic test) depends on the prevalence of the disease in a population (Sackett et al. 1991). In palliative care populations where prevalence of depression is known to be high, a positive diagnostic test is likely to indicate 'true' disease. If the prevalence in a primary care setting is higher, the performance of diagnostic tests in this setting will be even greater. However, if depression rates in primary care populations are lower, there is a greater risk of falsely identifying symptoms of emotional distress as indicative of a pathological state of depression.

The utility of the current theoretical account of depression in understanding emotional distress presenting to primary care depends in part on the prevalence of depression in a primary care population. To date, there have been no studies which have sought to measure depression rates in terminally ill primary care populations. Therefore I posed the question: what is the prevalence of depression in a primary care population with advanced metastatic cancer?

3.3 Aims & Objectives

AIMS:

- to assess the prevalence of ICD-10 major depression in a population of terminally ill cancer patients identified from a primary care setting.

OBJECTIVES:

- to identify a representative sample of patients with advanced metastatic cancer from GP Practices in Liverpool
- to conduct a two-phase depression prevalence survey
- to identify the prevalence of risk factors for depression in this population
- to comment on results in light of identified risk factors and in the context of previous study results

3.4 Ethical and Research Governance Approval

Before describing the methods for this study, I will first consider the ethical issues related to this research study. My proposal was to undertake non-curative research in a group of people who were likely to die before the research was completed. The research has potential to benefit other patients, however research ethics as defined in the Declaration of Helsinki (World Medical Organization 1996) state that the individual interests of research participants outweigh any potential benefits of research to wider society. I therefore needed to consider the potential impact of my proposed study on the intended participants, in order to ensure it was ethically justified.

Assessing the risk of harm (maleficence) and benefit (beneficence) in this type of research is complex. Potential risks identified from a theoretical consideration of the research included: upsetting patients, depriving them of energy and time by using it for research, and the risk of undermining their autonomy since they may feel obliged to take part in research by virtue of their need for health care. However, there were also potential benefits: the opportunity to talk, the right to make an autonomous decision to take part in research, and possibly some benefit from knowing they have contributed to work that will help others.

There has recently been some attempt to provide empirical evidence to support these theoretical considerations. Barnett (2001) reported self-identified benefits for participants in non-curative research involving people with terminal cancer. These included appreciation of an opportunity to talk things through; and restoration of a 'sense of purpose'. Although some participants reported experiencing transient upset, the overall risk-benefit ratio of involvement was positive (ibid).

Crighton et al. (2002) also described self-reported benefits for participants in non-clinical cancer trials. Participants were keen to be involved and help with research. Involvement in the study brought them reassurance that their personal illness experiences were common or 'normal'; and they valued the opportunity to share experiences with an educated listener who wasn't family. The research process also contributed to the revelation and confirmation of clinically significant symptoms that had not previously been reported to a clinical team.

The theoretical and empirical evidence suggests that research in this patient group may be conducted without compromising the ethical rights of individuals, and indeed that research may support individuals. Whilst being acutely aware of issues particularly of autonomy and non-maleficence, I felt there were sufficient ethical grounds to proceed with this study. My assessment of the ethical risk : benefit ratio was supported by Liverpool Local Research Ethics Committee, who granted ethical approval for the study including the qualitative study described in chapters 5-9 (see

Appendix A1). This was subsequently extended to include St Helens & Knowsley in order to support patient recruitment to the study. Research governance approval was obtained from the relevant Trusts. As a condition of my ethical approval, in each GP practice subsequently recruited to the study all partners were asked to give written consent for their patients to be included. Written consent was also obtained from all patients participating in the study.

Safety measures to prevent or deal with any (potential) harm to participants were put in place. As a registered and practising clinician, I have a duty of care to the patients I work with and to maintain professional standards. I also have skills in risk assessment, and management of adverse or difficult situations. Additional safety measures added for the purpose of this research study included the requirement for any clinical concerns arising from the research process to be reported back to the primary care team responsible for that patient. Where possible, this would be done with the consent of the patient. If consent was refused, patient confidentiality could be breached if I and my two clinically qualified supervisors considered the risk to warrant such a step.

3.5 Methodological approach

The question of how to estimate the prevalence of depression in this population group raises questions about both sampling and measurement tools. Prevalence studies in palliative care settings have commonly assessed consecutive patients attending, or being admitted to, a service, often using a clinician-led diagnostic tool (Wilson et al. 2000). However, in a primary care community setting with a dispersed population, clinician-based diagnostic assessment on every potential participant is not practical (Dunn 2000). There are difficulties in accessing every individual with terminal cancer; whilst diagnostic interviews performed by a clinician are time-consuming and resource intensive, especially if detection rates are likely to be low (ibid). Screening tools are quicker and easier to use than formal diagnostic tools, however they offer only an assessment of depression risk rather than prevalence (Wilson et al. 2000).

In recognition of these problems, community-based assessments of depression prevalence in non-palliative care settings have therefore used the two-phase survey design described by Dunn et al. (1999): for example, see Meltzer et al. (1995) or the ODIN study (Ayuso-Mateos et al. 2001). In the first sampling stage, a screening tool is used to stratify the population into high and low risk of depression. In Phase Two, sub-samples of these strata are assessed using a full psychiatric diagnostic tool (Dunn et al. 1999). Weighted prevalence estimates are calculated which allow for the two-stage sampling process (Dunn 2000). In light of the previous success of this methodology together with pragmatic concerns related to my study, I decided to adopt Dunn et al.'s (1999) approach for my prevalence survey.

3.6 Sampling

My aim was to identify a representative sample of patients with advanced metastatic cancer from General Practice lists in Liverpool. I first needed to identify practices willing to join the study. General practices in Liverpool were approached (see appendix A2.1 for a copy of the invitation letter). In the first recruitment round, all members of the Mersey Primary Care Research & Development Consortium (a primary care research network of eleven practices in Liverpool which seek to support and promote primary care research) were invited to join the study. These are research-active practices with both staff and patients having a greater awareness of, and involvement in, primary care research. Invitations were subsequently sent out to other practices in Liverpool, focusing for pragmatic reasons on larger ones. Sampling continued for as long as time permitted, bearing in mind my estimated sample size (see p24).

Patient lists were searched to identify all patients eligible to join the study. Inclusion and exclusion criteria are listed in Box 3.1. Existing depression or antidepressant treatment was not a contraindication to entry to the study. Searches were conducted by me (with ethical approval) in all but two practices, where the Partners identified eligible patients.

Box 3.1: Patient Inclusion and Exclusion criteria for prevalence survey

INCLUSION CRITERIA	EXCLUSION CRITERIA
• age over 18 years • diagnosis of advanced metastatic cancer • able to give informed consent • able to take part in an interview.	• severe cognitive impairment • unable to speak English • GP assessment of a patient as not suitable to be contacted for any reason (for example patient too ill, concerns over researcher safety).

Sample size calculations were based on prevalence estimates from previous studies in palliative care populations. Here the mean prevalence estimate of depression was approximately 20% (see Chapter 4, p56). To identify a prevalence of depression of 20% ± 5% in our study sample with 95% confidence would require a sample size of 246 (EpiInfo version 6).

3.7 Measurement

3.7.1 *Baseline measurement: risk factors*

Risk factors for depression in palliative care populations identified in the literature included: age, sex, previous history of depression, tumour type, social support, physical symptoms and functional impairment (Potash & Breitbart 2002, Wilson et al. 2000) (see also Chapter 4, p53). At the start of this chapter, I also indicated my interest in knowing whether palliative care offered protection from depression.

Ethical and pragmatic reasons meant I needed to be selective in what data on risk factors I collected. To collect data on everything would be time and resource intensive for me as a researcher, demand a lot from potentially very unwell participants, whilst ultimately not providing statistically useful information without achieving unrealistic sample sizes. Based on my review of the literature and knowledge of data collection mechanisms within primary care settings, I therefore selected the risk factors listed in Box 3.2 as the key factors to be identified at baseline data collection from GP-held patient records.

Box 3.2: Baseline risk factor data collected for eligible participants

- Age
- Sex
- Postcode (to identify socioeconomic status: see below)
- Tumour type
- Current depression (as assessed by the GP, no formal diagnostic tool required)
- Past history of depression
- Attendance at hospice

In the general population, it is known that depression is more common in deprived socioeconomic groups. (For example, see Meltzer et al. (1995) who demonstrated higher rates of depression associated with non-house ownership, cramped living conditions, non-car ownership, low social class, and unemployment.) Since some cancers are also more common in deprived populations, socioeconomic status was included within this study as a potential confounding factor. Individual postcodes were converted to an Index of Multiple Deprivation (IMD) ranking as provided by the National Statistics Neighbourhood Statistics database (National Statistics 2004). The IMD divides England into 32,482 areas, and calculates a deprivation score for each based on a number of variables. Areas are subsequently ranked, with 1 indicating the most deprived area (ibid).

3.7.2 *Assessment of depression status*

Phase One (Screening): All eligible patients were sent an invitation to join the study from their GP. Along with a covering letter, patients were sent an information leaflet about the study, a consent form, and a brief screening questionnaire for depression - the Edinburgh Depression Scale, EDS (Cox 1987) (see appendices A2.2-5). The EDS has been identified as a suitable screening tool for depression in this population (Lloyd-Williams et al. 2000) It is short, consisting of ten questions (see appendix A5); and does not ask about the presence of physical symptoms which may contribute to a diagnosis of depression (see p63-65) but are also common in patients with cancer. The maximum possible score on the EDS is 30; a score of 13 or above is considered to indicate high risk of depression with a reported sensitivity of 81% and specificity of 79% (Lloyd-Williams et al. 2000).

Those who didn't reply were sent one follow-up letter after two weeks, including a further copy of the EDS, information leaflet and consent form. Those not replying to the second letter were recorded as non-responders. For those returning questionnaires, their EDS score was calculated and used to assign people into one of two groups: high risk (EDS score $\geq$ 13), or low risk (EDS score <13).

Phase Two (Diagnosis): In Phase Two, a sub-sample from each of the two groups identified in Phase One were assessed using the revised Clinical Interview Schedule (CIS-R), a validated psychiatric diagnostic tool which identifies psychiatric diagnoses based on the ICD-10 classification system (Lewis et al. 1992). It is suitable for use by lay researchers or indeed clinicians with no formal psychiatric training and consists of fourteen sections each covering a particular symptom cluster (for example, fatigue, worry, depression, irritability). On completion of the tool, each patient is awarded a score: a score of 12 is taken to indicate the presence of a psychiatric disorder. Lewis has subsequently developed a computerised version of the CIS-r which identifies specific psychiatric diagnoses (using ICD-10 criteria) for patients who have a score of ±12 (Lewis 1994). I obtained a copy of the computer programme from Lewis for use in this study.

Other researchers have developed their own algorithm to convert CIS-r responses into ICD-10 diagnoses: for example see Meltzer et al. (1995), and the EMPIRIC study (Sproston & Nazroo 2002). Both identified responses to questions in the CIS-r which provided evidence of symptoms diagnostic of depression as identified in the ICD-10 classification (World Health Organisation 1992). However, whereas Meltzer et al. (1995) included the requirement for a minimum score of 12 to trigger a diagnostic process (as per the original description by Lewis et al. 1992), Sproston & Nazroo (2002) omitted this requirement. The effects of different approaches to scoring the CIS-r on overall prevalence estimates have not been previously assessed. I therefore compared the use of the computer algorithm and Meltzer et al.'s (1995) algorithm in assessment of depression prevalence.

All patients from the Phase One high risk group were invited to complete the CIS-r. I aimed to sample an approximately equal number from the low risk group to be included in Phase Two. Given that I had estimated 20% of the population would be depressed, I therefore aimed to enter a random sample of 20% of the low risk group into Phase Two.

3.7.3 *Follow-up data*

Time to death was considered a possible risk factor for depression, but may also influence response rate. Therefore six months after patients were originally invited to join the study, follow-up data was obtained for both responders and non-responders identifying whether the patient had died within six months of the initial invitation.

3.8 Planned analysis

Analysis was undertaken using SPSS for Windows, version 13. Planned analyses included:

1. A comparison of baseline characteristics of responders and non-responders (including mean age, sex, SES, tumour type, current/past history of depression, attendance at a hospice); also probability of death within six months of the study.
2. Weighted prevalence estimate of depression as per the method of Dunn (2000).

3. A comparison of risk factors in those with and without depression (including age, sex, socioeconomic status, past/current history of depression, attendance at a hospice).

3.9 Results - Sampling

Data collection continued for two years. By the end of this time, 51 of the 105 GP Practices in Liverpool had been contacted. 13 Practices joined the study; patient identification was repeated within two of the Practices. Table 3.1 gives details of the thirteen Practices in the study. Figure 3.1 summarises the flow of patients through the study. 'Responders' were those who replied in some way to one of the invitation letters (n=83). However 13 of those were unable to complete the EDS because they were too ill, unwilling, or had died. In total, 70 people completed the EDS and were included in the final study sample (identified in Figure 3.1 and Table 3.4 as 'Completers').

Table 3.1: Showing the characteristics and response rates from the 13 Practices in the study

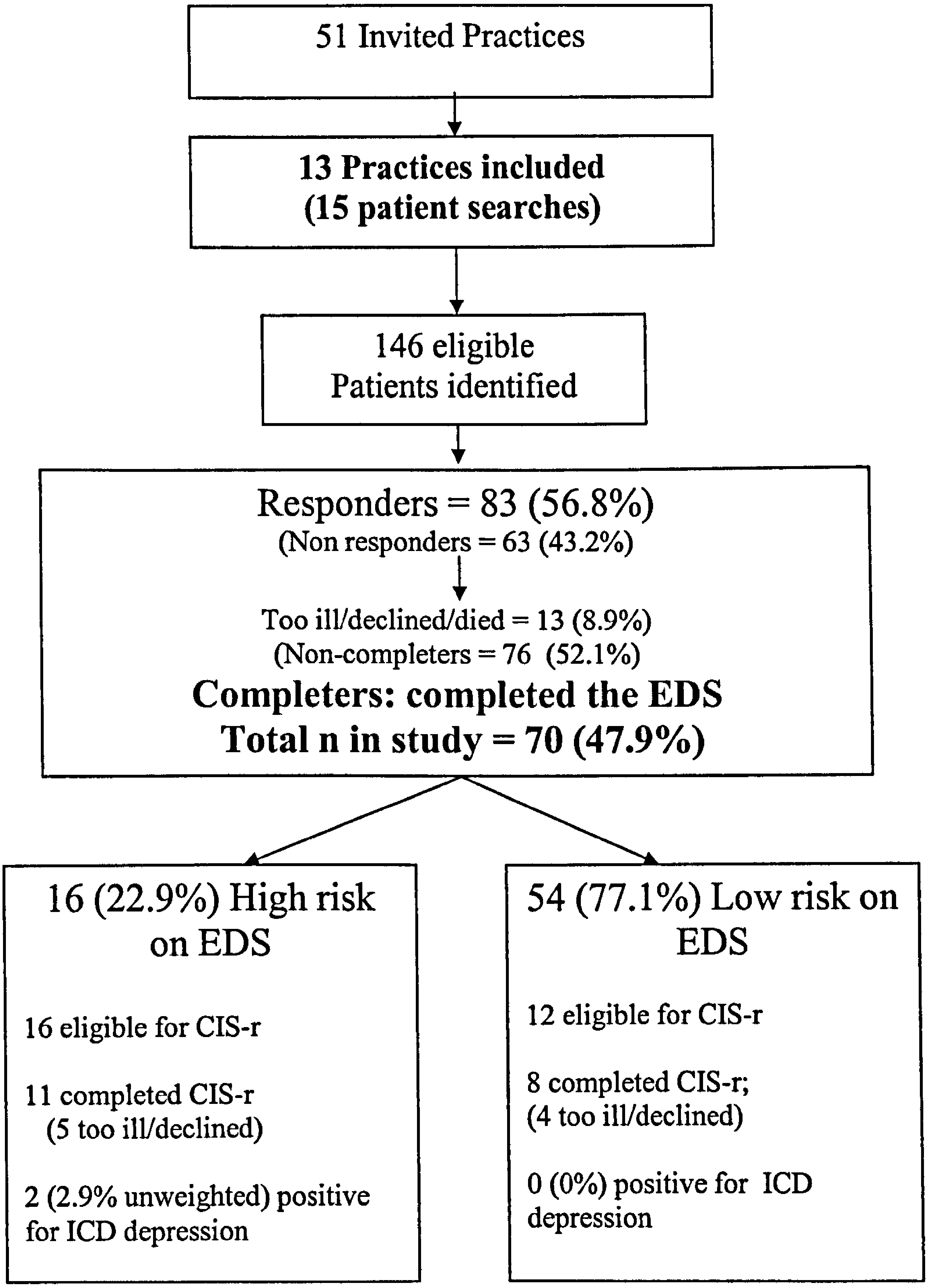
Reference	Area IMD rank	No. of WTE Principals **	Date of invitation letter	No. eligible patients identified	No. patients who responded (%)
A*	436	2.75	January 04	20	14 (70%)
B	33	1	February 04	4	2 (50%)
C1* C2*	100	6.75	March 04 Sept. 05	16 12	10 (62.5%) 4 (33.3%)
D	8,527	3	May 04	5	1 (20%)
E*	3.559	5.75	June 04	15	11 (73.3%)
F1 F2	1,791	4.5	August 04 October 05	16 9	11(68.8%) 7 (77.8%)
G	53	4.75	Sept. 04	4	2 (50%)
H	313	3.5	October 04	8	5 (62.5%)
I	980	2	February 05	5	2 (40%)
J	4.072	3	February 05	11	5 (45.5%)
K	3,940	2	April 05	7	2 (28.6%)
L	4,006	2.5	August 05	7	2 (28.6%)
M*	3,067	6.75	November 05	7	4 (57%)

IMD = Index of Multiple Deprivation (1= most deprived, see page 25)

* = member of Mersey Primary Care Research & Development Consortium

** Number of Whole Time Equivalent (WTE) Principals (data from Mersey Central Operations, personal communication)

Figure 3.1: Showing the flow of patients through the prevalence study



An additional 4 low-risk patients underwent a CIS-r interview in the piloting stages of the project. As these were not part of the random sample, they are not included in the subsequent prevalence analysis. None had an ICD diagnosis of depression.

3. 10 Results: depression estimates

As outlined in Figure 3.1, 16 patients were identified as high risk, of whom 11 completed the CIS-r and two were found to meet the criteria for ICD-10 depression. 54 patients were identified as low risk. A random sample of 12 was identified as eligible for Phase Two, and eight completed the CIS-r. None met the criteria for ICD-10 depression. Table 3.2 summarises these results.

Table 3.2 Showing the CIS-r results for the study sample of 70

	High risk (EDS score≥13) N = 16 (22.9%)	Low risk (EDS score<13) N = 54 (77.1%)
Number eligible for CIS-r	16	12
Number completing CIS-r[†]	11	8
Number with depression - using computer algorithm - using Meltzer's (1995) algorithm	 2 * 2 (but not the same 2 as *)	 0 0

[†] Reasons for not completing CIS-r: too ill (3), declined (4), died before interview (1)

[*] The results identified using Lewis's (1994) computer algorithm are used in the subsequent calculations.

Prevalence estimates were calculated considering the two-stage sampling process Dunn (2000). In effect, each individual in Phase Two (for whom CIS-r data was available) represented a number of individuals from the Phase One sample, and therefore contributed a weighted sum to the final prevalence estimate. The first step was to calculate the relative weights. CIS-r data was available for 11 out of 16 high risk patients and 8 out of 54 low risk patients. Therefore 11 high risk patients in the Phase Two sample represented 16 patients from the Phase One sample. Their results were weighted by a factor of 16/11 or 1.45. Twelve low risk patients in the Phase Two sample represented 54 patients from the Phase One sample. Their results were therefore weighted by a factor of 54/12 or 4.5. The calculation of the weighted prevalence estimate (including 95% Confidence Intervals) is shown in Box 3.3.

Box 3.3: Calculating the weighted prevalence estimate

Weighted prevalence = (no. of cases in high risk group x 1.45) + (no. of cases in low risk group x 4.5) / total no. in Phase One sample

$= (2 \times 1.45) + (0 \times 4.5) / 70$

$= 0.041$

Weighted prevalence = 4.1%

To calculate the 95% Confidence Interval (CI) for this estimate, the Standard Error is calculated using the method of Dunn (2000)

Total Phase One sample size $N=70$
Number identified as screen positive (ie high risk) $N_1=16$
Proportion screen positive $W_1=0.22857$
Number identified as screen negative (ie low risk) $N_2=54$
Proportion screen negative $W_2=0.771429$

Number of screen positives in Phase Two $M_1=11$
Number identified as cases (ICD depression) at Phase Two $D_1=2$
Proportion disease $P1= D_1/ M_1 = 0.181818$

Box 3.3: Calculating the weighted prevalence estimate

Number of screen negatives in Phase Two $M_2=8$

Number identified as cases/depressed at Phase Two $D_2 = 0$

Proportion diseased $P_2 = D_2/M_2 = 0/8 = 0$

$SE = \text{sq rt} [W_1^2P_1(1-P_1)/N_1 + W_2^2P_2(1-P_2)/N_2 = (P_1-P_2)^2W_1W_2/N]$

$= 0.02385$

$95\%CI = 0.0416 \pm(1.96x0.023854)$

$= 0.0416 \pm 0.046754$

$= -0.05 - 0.088$

We can be 95% confident that the true prevalence lies between 0 and 8.8%

3.10.1 *Characteristics of the identified depressed patients*

Only two patients were identified as depressed. Both depressed patients were female with a mean age of 68 years; the mean age of the non-depressed group was 65.2 years. Given the small numbers involved, no formal statistical analysis was undertaken. Table 3.3 shows that depressed status was not associated with previous or current GP diagnosis of depression, hospice attendance or time to death. Although there is an apparent large gap in socioeconomic status (SES) between depressed and non-depressed participants, this was not statistically significant: p=0.819 (Mann Whitney-U test, SPSS version 13). Clearly larger numbers would be needed to assess whether this is a genuine effect or random error.

Table 3.3: Showing characteristics of depressed and non-depressed participants

	Depressed (n=2)	Not depressed (n=68)
SES (mean rank)	3753	5471
Tumour	1 lung, 1 breast	
Current depression	1 yes, 1 no	6 yes, 61 no, 1 missing
Previous depression	2 no	56 no, 12 yes
Attends hospice	1 yes, 1 no	23 yes, 44 no, 1 missing
Died within 6 months of study*	2 no	42 no, 12 yes, 4 missing

3.11 Discussion

The study identified a prevalence of depression of 4.1% in a sample of terminally ill cancer patients (95% CI 0-8.8%). This is lower than that identified in the majority of existing palliative care studies (Hotopf et al. 2002, Stiefel et al. 2001,Wilson et al. 2000). The results suggest the need for caution in extrapolating clinical guidance from a palliative care setting to a primary care setting. However, before drawing final conclusions, I first consider the strengths and weaknesses of my study in order to assess the validity and utility of the results.

3.11.1 *Sampling*

The final sample size was lower than I had aimed for - the result of the time and resource intensive nature of this sort of survey. It is also consistent with that obtained in many previous studies (see Chapter 4, p67). However, the original sample size calculations were also inaccurate given that actual depression rates were much lower than those predicted from the literature. The sample size required to detect a prevalence of 4% (range 0-8%) is 92 (EpiInfo 6). The final sample size was therefore not inappropriate.

A non-random sample of Practices in Liverpool was recruited to the study, with a Practice response rate of 25.5%. All eligible patients from participating Practices were invited to join the study but the final individual response rate was just 47.9%. I will therefore consider the potential effects of sampling at both the Practice and individual level on the representativeness of my sample, and therefore whether any general conclusions can be drawn from my results.

<u>Sampling at the Practice level</u> (Table 3.1, p29)

All the Practices in this study were based in areas of significant relative socioeconomic deprivation as evidenced by the Index of Multiple Deprivation ranking. All 13 fell within the top 26% most deprived areas in England, and most (n=8, 61%) within the top 10%. With lower socioeconomic status a risk factor for depression in the general population (Meltzer et al. 1995), this study based in a deprived city such as Liverpool might be expected to identify higher rates of depression than would be detected elsewhere in the country.

Selection of Practices for the study was based largely on pragmatic grounds targeting larger Practices and/or those known to have been previously involved in research. Better response rates were seen in practices which were members of the Mersey Primary Care R&D Consortium (mean response 59.2% versus 47.2% in non-consortium practices, although not statistically significant p=0.24). There was a non-statistically significant correlation between practice size (number of WTE Principals) and response rate (r=0.355, p=0.194). Practice A had one doctor with a special interest in palliative care who contacted all patients by telephone and personally invited them to join the study. This may explain the higher response rate at this practice. The drop in response rate for the second data collection round at Practice C (C2 compared with C1) may be associated with the reduced death rate in the second sample. The second search may have selected a group of people who had more recently been diagnosed with terminal illness and this may have influenced response. However at an individual level, an improved 6 month survival rate was predictive of joining the study rather than non-response (see Table 3.4). Whilst a more recent diagnosis does not necessarily equate with a better survival rate, these inconsistencies in the data remain unexplained.

The lower response rates seen in most of the practices sampled in 2005 is probably explained by the move to practices with less previous research experience. This is an interesting observation. I had expected that practice teams with little research experience may have hesitated to join a study, but that the effect would not be discernible at a patient (recruitment) level. In reality, practice teams were equally enthusiastic; the lower response rate seems to reflect patient agendas, which may include a reduced expectation and awareness of research in a primary care setting. The need to promote awareness of research amongst patient groups in primary care settings in order to support future research projects is arguably one finding from my data.

Although response rates were lower from smaller practices and those with little previous research experience, in all but one there was still some response. I have therefore succeeded in sampling patients from a range of practices in Liverpool - geographically located in the North and South of the City with different sizes and in areas of varying deprivation. However, ultimately this was a non-random sample, the effect of which on the final outcome is unquantifiable. The non-random sampling of practices is therefore a weakness of the study and limits the extent to which results can be generalised across the UK.

Sampling at the Patient level

The study method excluded people with cognitive impairment and those who were unable to take part in an interview in English. Whilst this reflected pragmatic reasons such as the lack of funding for interpreters, it was also the case that the measurement tools were not available in other languages. This limitation in my sampling limits the applicability of results to non-English speaking populations.

Table 3.4 compares the characteristics of patients included in the Phase One sample (completers of EDS) and those who were unable to be included (non-responders or respondents who were too ill/declined to take part: so-called non-completers). The final response rate was 47.9%. This reflects the difficulty of recruitment in primary care research generally, but is also consistent with completion rates in previous studies in a secondary care setting (see chapter 4, p67).

Table 3.4: Comparing baseline and follow-up characteristics of completers and non-completers of EDS

	NON-COMPLETERS (n=76)			COMPLETERS (n=70)			P value for difference
Mean age (Standard Error) (years)	71.6 (1.25)			65.3 (1.55)			0.002$^{\$}$
Sex	47 (61.8%) women			42 (60%) women			0.820
Socioeconomic Status (mean rank Index of Multiple Deprivation)	4165.63			5422.79			0.489 $^{\&}$
Tumour type	26 lung, 16 GIT, 13 breast, 5 haematological, 3 gynaecological, 9 urology, 2 head and neck			21 lung, 16 GIT, 12 breast, 7 haematology, 5 gynaecology, 5 urology, 3 head&neck, 1 skin			0.782
	YES	NO	MISSING	YES	NO	MISSING	
History of depression	15 (19.7%)	61 (80.3%)	0	12 (17.1%)	58 (82.3%)	0	0.687
Current depression	15 (19.7%)	61 (80.3%)	0	7 (10%)	62 (88.6%)	1	0.159
Hospice attendance	18 (23.7%)	49 (64.5%)	9	24 (34.3%)	45 (64.3%)	1	0.027
Died within 6/12 of study	37 (48.7%)	34 (44.7%)	5	13 (18.6%)	53 (75.7%)	4	<0.0005

(Analysis for p value = chi squared, t test $^{\$}$, or Mann Whitney U$^{\&}$)

There was no statistical difference between completers and non-completers in terms of sex, socioeconomic status or tumour type.

The final sample did differ significantly from non-completers in terms of age: the mean age of non-completers being 71.6 years compared to 65.3 years in the completers (p=0.002). Age is accurately recorded in GP records: the observed difference is likely to be a real difference in the sample. With age a reported risk factor for depression, the possibility of higher depression rates (perhaps closer to the previously reported mean of 20%) in non-completers is raised. However, whilst the difference is statistically significant, it is unlikely that an age difference of 5 years could account for a difference in prevalence of 4.1% in my study compared with a mean of 20% from previous studies.

The final sample was more likely to be attending a hospice than the non-completer group (34.3% versus 23.7%, p=0.027). The potential impact of this on study outcomes is not clear but may suggest that the final sample is more symptomatic (and therefore in greater need of palliative care support) than the non-completing group. However, it may be that those attending secondary care services have had greater contact with, and experience of, research and are more likely to want to take part in a study. The difference may also be an artefact of measurement. Hospice status of the non-completer group is based purely on GP records; for completers, status was confirmed by asking the patient. Precision of measurement is therefore likely to be much greater in the completer group.

Non-completers were more likely to have died within 6 months of the study than completers: 48.7% of non-completers compared with 18.6% of completers (p<0.0005). Implications for observed results are unclear. However, data suggest that my sample was further from death and therefore possibly less unwell than the non-completers. This observation may help explain why the prevalence of depression in this sample was lower than in previous studies of secondary care populations who may well have been closer to death. My study may therefore have sampled people at an earlier stage of their disease progression than those conducted particularly in palliative care settings.

The low identified depression prevalence in this study on the background of an overall response rate of only 47.9% raises the concern that the 'true' level of depression in the community may be higher. In other words depressed people were less likely to respond to the study invitation, not least because of their illness. Table 3.4 shows that there was no statistically significant difference in past or current depression status between completers and non-completers. This suggests that the identified low burden of depression may not simply be an artefact of non-response. However, there was a non-statistically significant higher current depression rate in non-responders (19.7%) compared to responders (10%); lack of statistical significance may be a type 2 error resulting from the small sample size.

As is described in the review of previous studies in the next chapter, many of the limitations in my study in terms of non-response and small sample size apply equally to existing reported studies. For example, response rates varied from 15 to 100% in studies which surveyed patients directly (see Table 4.3, p67). Similar concerns with depression rates being higher in non-responders apply. Therefore whilst the precision of my estimate of depression prevalence may be questioned, I feel that the observed difference compared to previous palliative care studies is likely to be 'real'. Depression rates in primary care, at least in my sample, are lower than previously identified in palliative care studies.

3.11.2 Discussion: measurement

The precision of measurement of some risk factors - for example hospice use - has already been raised. Depression status as detailed in Table 3.4 was based on GP records. Whilst there are acknowledged weaknesses in this approach (notably problems with under-recording or under-identification when searching records) there was no reason to suspect a systematic difference between completers and non-completers. Some of the data may be imprecise, but there was no evidence of bias. However, results identified in this study did raise issues about the use of both the EDS and the CIS-r. I now turn to consider how each may have impacted on the final results.

Phase One: the EDS

Previous studies have reported a sensitivity of 81% and specificity of 79% with a Positive Predictive Value (PPV) of 53% in a palliative care population (Lloyd-Williams et al. 2000). In this study of a primary care population, there were a significantly higher number of false positives than would have been predicted from past research. Table 3.5 shows the results for all patients where both CIS-r and EDS data were available (including the four pilot patients non-randomly selected from the low risk group and excluded in the earlier analysis). For the 23 patients with both a CIS-r and an EDS outcome, results showed the EDS demonstrated a sensitivity of 100% (2/2) but specificity of only 57% (12/21). The PPV was just 18% (2/11), reflecting in part the low prevalence of depression in the population. The Negative Predictive Value (NPV) was however 100% (12/12).

Table 3.5: Showing CIS-r diagnoses for EDS positive and negative screening results

		Screening tool result		
		EDS +	**EDS -**	
Diagnostic tool result	**CISR+**	2	0	2
	CISR-	9	12	21
		11	12	23

The reduced specificity of the EDS in the population sampled in this study will have increased the numbers entering Phase Two from Phase One. However, a sensitivity of 100% should mean that all potentially depressed patients were entered into Phase Two.

Theoretically, the sensitivity and specificity of a screening tool should remain constant in different populations, although the PPV will vary according to the prevalence of the disease within the given population (Sackett et al. 1991). This was not the case in my study, suggesting there was something different about the performance of the tool within the two populations. This may reflect a difference in the nature of the 'depression' being measured by the tool, adding weight to Gallo's (1997) assertion that we need a primary care specific conception of mental illness. Alternatively the measurement process may differ in the two settings, for example patients in palliative care and primary care may respond differently to the EDS questions for reasons that are not related to the presence or absence of mental illness.

The altered performance of the tool has implications for research and clinical practice. Further work is needed to determine whether the EDS would be a useful screening tool in primary care practice. With a significant risk of a false positive result with the current tool, there may be a need to amend the cut-off level or indeed identify an alternative tool. Based on data from my sample, a new cut-off level of 18 gave a sensitivity of 90% (specificity of 100%). However, with only two patients having a positive CIS-r diagnosis, it is hard to comment meaningfully on an appropriate cut-off for clinical practice. Further research would be needed to clarify this point.

Phase Two: the CIS-r

Inconsistencies in the results identified from different approaches to scoring the CIS-r were identified. The computer algorithm and the Meltzer (1995) algorithm both required a cut-off score of 12 for a diagnosis to be made, consistent with the development and validation of the original tool (Lewis 1992). Both approaches identified two people in my sample as depressed; however only one patient appeared in the depressed group with both methods. Thus whilst the same number of depressed people were identified, there were differences in who was identified.

The EMPIRIC study omitted the requirement for a minimum overall score of 12 on the CIS-r questionnaire to be present before a psychiatric diagnosis was assigned (Sproston & Nazroo 2002). Re-analysis of my data omitting the requirement for a score of 12 prior to diagnosis led to one further patient from the high risk group being identified as depressed (giving a new total n=3). The requirement for a cut-off of 12 ensures a level of symptom burden that warrants a psychiatric diagnosis (Lewis et al. 1992), and may arguably be an attempt to reflect the 'clinical instinct' of trained psychiatrists: it is likely to give a more precise result. However in clinical practice, a GP may diagnose depression if just some of the symptoms listed in the ICD-10 diagnostic criteria are present. Omitting the cut-off may better reflect clinical practice. Indeed the rates of current or previous depression recorded in patients' GP notes are closer to the reported prevalence of depression identified in palliative care research. It is uncertain which diagnostic approach is best; the discrepancies highlight the inconsistencies in diagnosis and measurement.

The CIS-r is an extensively used diagnostic tool, well validated in a number of population groups. Previous community based studies of depression have used the CIS-r (Sproston & Nazroo 2002, Meltzer et al. 1995). However it has not been widely used or validated in a palliative care population. As with the problems highlighted for EDS, further work may be needed to test the suitability of the CIS-r, or even the need to develop an alternative tool.

My data raise questions about the validity and reliability of measurement tools in depression research in palliative care - questions which also have implications for clinical practice. I will consider these issues in greater depth in Chapter 4.

3.11.3 *Discussion: analysis*

I will briefly raise a question about the implications of combining a subtle realist ontological stance with a positivist epistemology and hence a statistical methodology which relies on an assumption of truth.

The statistical analysis reported in this chapter assumes that there is a true (and identifiable) prevalence of depression in the global population of all primary care patients with terminal cancer. Statistical theory allows me to quantify how close the results obtained from my study sample are to that 'true' answer (Altman 1999). However a subtle realist ontological stance does not include an assumption of the existence of a 'true answer'. I do not believe the subtle realist stance negates the use of statistical theory since it does not reject the existence of a 'truth'; it simply states that we cannot be sure whether it exists. Thus my ontological stance raises some uncertainty about what my statistical analysis is telling me. It remains a little unclear what it is that I am 95% confident that I am 'close to'. It therefore prompts reflections over the nature of the knowledge produced by this methodology, something I have identified as an important part of this thesis and understanding clinical practice. However I do not believe it invalidates the approach.

3.12 Summary and Conclusions

The findings reported in this chapter identified a prevalence of depression in a primary care based sample of patients with advanced metastatic cancer of 4.1% (0-8.8%). Problems with identifying the impact of the non-random sample of Practices included in the study on final results have been highlighted. Although individual completion rate of the Phase One survey was only 47.9%, the only statistically significant differences between completers and non-completers were with regards to age and time to death. There was a non-significant higher rate of current (GP diagnosed) depression in non-responders, but overall results suggest that depression rates were truly lower in this population when compared to the majority of previous studies in palliative care settings. With only 18.6% of respondents dying within six months of the study period, the study has possibly identified a sample of patients who were further from death than those in previous secondary care based studies. This may help explain the lower depression rates seen.

The findings in this chapter indicate that we should exercise caution in extrapolating findings from palliative care research into primary care practice. The depression rate was lower than predicted by previous studies, with a potential impact on the post-test probability when using diagnostic tests in this population. As Gallo (1997) argued, we need primary care specific research to understand the application of theoretical concepts of mental illness pathology.

However the study also raised questions about the processes by which knowledge is identified - about the research process. Measurement tools performed differently in this different population than when used in the palliative care settings in which they were validated. It was therefore unclear whether the observed difference between primary care and palliative care rates of depression reflected perhaps variation in risk factors and causal elements, or was simply an artefact of measurement.

Identifying the utility of a biomedical account of depression to understand and treat emotional distress depends on being able to confirm the validity of the knowledge base. In the next chapter, I will take a closer look at the wider research base from which this knowledge derives to try to clarify questions about the validity and therefore utility of this knowledge base in understanding clinical practice.

Chapter Four: Reviewing the existing palliative care literature

4.1 Introduction

In Chapter 3, I identified a lower rate of depression in a terminally ill primary care population than would have been predicted based on previous research in palliative care populations. If true, the results would suggest that applying palliative care guidelines in General Practice could lead to inappropriate care. However my study also raised questions about measurement artefact: the effects of the research process on the production of knowledge. I questioned whether the variation in reported rates of depression between studies is a 'true' difference, perhaps arising from variation in risk factors and causal elements, or an artefact of the research process.

In order to investigate the discrepancies between my study and previous ones, I undertook a critical comparative review of published prevalence studies and my own. I sought to comment on whether the observed differences are 'real' or artefact. I identified two hypotheses which I proposed to explore through the literature review:

- that higher rates of depression are explained by higher prevalence of risk factors in the identified samples;
- that higher rates of depression are found in studies with poorer methodological quality, including those with a less tight definition of depression (and not corrected for use in palliative care populations), or non-validated tools.

Based on this review, I sought to draw conclusions on the utility of a biomedical knowledge base in informing clinical practice in this area, and offer suggestions for future research and development in this area.

4.2 Methodology

4.2.1 *Identifying studies for review*

A search of MEDLINE and PsycINFO was undertaken using the terms 'depression' and 'prevalence' and 'cancer' or 'palliative care/medicine'. 396 studies were identified and screened using the following inclusion criteria: outcome includes measurement of prevalence of depression, >90% patients with advanced cancer (metastatic disease, terminal diagnosis), and which studies used a psychiatric interview not a screening tool (see Box 4.1).

Box 4.1: Diagnostic versus screening tools for depression

Depression-rating scales are screening tools which have been developed to overcome the practical difficulties of using long diagnostic interviews in very ill populations. The Hamilton Rating Scale for Depression (HRSD) can be completed following a 30 minute interview, and is viewed as the gold standard for rating scales (Gotlib & Hammen 2002). Studies report inter-rater reliability coefficients of at least 0.84 (ibid). Despite demonstrable utility and reliability, it has been criticised for focusing on external assessment of somatic symptoms over self-reported distress (Freeman & Tyrer 1992). Self-report scales have also been developed, for example the Hospital Anxiety and Depression Scale (HADS). This has been widely used in medically ill populations, including palliative care settings since it does not include somatic symptoms of depression such as fatigue or pain (Stiefel et al. 2001).

However these are not diagnostic tools. Sensitivity and specificity of individual tools vary in different populations (Stiefel et al. 2001) but tools have an average sensitivity of 0.78 and specificity of 0.71 (Wilson et al. 2000). Thus around 22% of depressed patients will not be identified as depressed whilst 29% will receive a false positive rating. In a review of the HADS, acute stress reactions contributed to false positive results, whilst social desirability (giving a socially expected answer) was considered a confounding factor in false negatives (Stiefel et al. 2001). As with all screening tools, improved sensitivity is associated with reduced specificity (Ciaramella & Poli 2001). Wilson et al. (2000) suggest rating scales should be seen as indices of general distress rather than measures of depression.

Prevalence studies using rating scales do not adjust for (or often even acknowledge) this imprecision. Therefore all studies using rating scales were excluded from this review.

363 papers were excluded at the abstract stage. 87 were reviews; 78 used a screening tool only; 124 had patients with an alternative or non-active cancer diagnosis; 65 did not include assessment of patient depression as an outcome; seven were not available in English; two were letters; and two were basic science studies. 33 abstracts remained; ten further studies were identified from reference lists. These 43 studies were reviewed in full. Nine were rejected as they did not deal with advanced disease; 16 were rejected because they used a screening tool. Thus 18 studies were included in the final review. For each study, data on sampling methods, risk factors in the sample population, and measurement tools used to estimate prevalence was extracted.

Summaries of the 18 studies together with my prevalence study from Chapter 3 are summarised in Table 4.1 starting on the next page.

Table 4.1: Summarising the prevalence studies included in the review

Notes For Table 4.1:
* = Reference code used in Tables 4.2 and 4.3
NR = not reported
HR = high risk, MR = moderate risk, LR = low risk (see Table 4.2)
MMSE = Mini Mental State Examination
Karnovsky score is a measure of functional impairment: < 45 = disabled and requires special assistance
SCID = Structured Clinical Interview for DSM-III-R

*	Author details	Setting	Response rate (r) No. in sample (n)	Risk factors	Measurement tool; Diagnostic classification	Prevalence (%)
A	Hardman et al. (1989)	Oncology unit inpatients, UK	r = NR n = 126	57% male; mean age 46.1 years (HR)	Validated tool : Standardised Psychiatric Interview; ICD criteria	3.2
B	Minagawa et al. (1996)	Palliative care inpatients, Japan	r = 85% n = 96	59% male; mean age 67.2 years; mean Karnovsky score, K = 45 (disabled) (HR); excluded patients with MMSE < 24 (LR)	Validated tool: SCID; DSM criteria	3.2
C	Reeve (2006)	Primary care, UK	r = 48% n = 70	40% male; mean age 65.3 years; 18.6% died within 6 months of study	Validated tool: CIS-r; ICD criteria	4.1
D	Akechi et al. (2002)	Oncology outpatients, Japan	r = 80% n = 129	74% male (MR); mean age 61 years; 50% with mild/tolerable pain (MR); 3% with poor function (LR); patients excluded if MMSE<24; 84% satisfied with social support (LR); 50% with <10 years education (HR)	Clinical interview; DSM criteria	4.7

*	Author details	Setting	Response rate (r) No. in sample (n)	Risk factors	Measurement tool; Diagnostic classification	Prevalence (%)
E	Maguire et al. (1999)	In- and out-patient oncology unit, UK	r = 40% n = 59	54% male; mean age 69 years; 60% reported pain (HR)	Validated tool: Psychiatric Assessment Schedule; DSM criteria	5
F	Akechi et al. (2004)	In- and out-patient palliative care unit, Japan	r = 27% n = 209	70% male (MR); mean age 60.8 years; mean pain score = moderate (MR); mean Karnovsky score = 75 (self caring) (LR); excluded patients with MMSE<24; only 15% with no confidante, 6% living alone (LR); 29% with <9 years education (MR)	Validated tool: SCID; DSM criteria	6.7
G	Chochinov et al. (1995)	Inpatients palliative care unit, USA	r = 26% n = 199	49% male; mean age 70.9 years (LR); 49% reported moderate or greater pain (MR); mean K = 49.3 (HR); 47% lived alone (HR); 69% with < high school education (HR)	Validated tool: Schedule for Affective Disorders & Schizophrenia (SADS); Research diagnostic criteria	8

*	Author details	Setting	Response rate (r) No. in sample (n)	Risk factors	Measurement tool; Diagnostic classification	Prevalence (%)
H	Chochinov et al. (1994)	Inpatients, palliative care unit, USA	r =26% n = 130	53% male; mean age 71.5 years (LR)	Validated tool: SADS; Research diagnostic criteria and Endicott criteria	9.2
I	Durkin et al. (2003)	Inpatients, palliative care unit, UK	r = 100% (C) n = 224	Not stated for whole sample	Non validated tool (clinical record review); ICD criteria	13
J	Hughes (1985)	In- and outpatients, oncology unit, UK	r = NR n = 50	76% male (MR); mean age 67 years	Clinical interview; own identified criteria for depression excluding somatic symptoms	16
K	Weitzner et al. (1999)	Outpatients, palliative care unit, USA	r = 73% n = 44	59% male; mean age 69 years; mean K = 40 (HR); mean 13 years of education	Validated tool: SCID; DSM criteria	16

*	Author details	Setting	Response rate (r) No. in sample (n)	Risk factors	Measurement tool; Diagnostic classification	Prevalence (%)
L	Breitbart et al. (2000)	Inpatients palliative care unit, USA	r = 59.7% n = 92	40% male; mean age 65.9 years; 78% with mild-moderate pain in last two weeks (LR); excluded if MMSE<24 (LR); 42% had more than high school education (LR)	Validated tool: SCID; DSM criteria	17
M	Le Fevre et al. (1999)	Inpatients, palliative care unit, UK	r = 28% n = 79	44% male; mean age 68.3 years	Validated tool: CIS-r	18
N	Radbruch et al. (2003)	Inpatients palliative care unit, Germany	r = 100% (C) n = 1304	46% male; mean age 65.1 years; 79% moderate – severe pain (HR); 76% had moderate – severe impairment (HR); 3.1% socially isolated (LR)	Non-validated/own assessment tool (clinical record review); ICD criteria	19.6
O	Lloyd-Williams & Friedman (2001)	Outpatients, palliative care unit; UK	r = 63% n = 100	44% male; mean age 57.3 years (MR)	Validated tool: Present State Examination; ICD criteria	22

*	Author details	Setting	Response rate (r) No. in sample (n)	Risk factors	Measurement tool; Diagnostic classification	Prevalence (%)
P	Brown et al. (1986)	Inpatients palliative care unit, USA	r = 15% N = 44	50% male; selected for pain and /or severe disability (HR)	Non-validated tool: clinical interview; DSM criteria	25
Q	Power et al. (1993)	Inpatients palliative care unit, Ireland	r = 90% n = 81	51% male; mean age 69.3 years; 34% had reduced cognitive function, 10% were borderline (HR)	Non-validated tool: clinical assessment; DSM criteria	26
R	Walsh et al. (2000)	Palliative care in- and outpatients, USA	r = 100% (C) n = 1000	55% male; mean age 65 years; median number of physical symptoms (pain, fatigue etc) = 11 (HR); 54% had poor function (HR)	Non-validated tool, clinical assessment interview ; own criteria for depression	41
S	Bukberg et al. (1984)	Inpatients oncology unit, USA	r = 69% n = 62	52% male; mean age 51 years (MR); sever physical discomfort in 35% (HR); 22% with poor, 23% moderate, 58% good functional status (MR); 89% lived with family, 95% reported good/excellent social support (LR); 53% social class I or II (LR)	Non-validated tool: clinical interview; DSM criteria	42

Statistical modelling to identify the relative contribution of each factor in the risk of depression was not possible, since heterogeneity of existing studies (in terms of study design and measurement processes) is a contraindication to pooling of study results. I therefore undertook a qualitative comparison of the studies identified in order to understand further the effects of risk factors and measurement artefact on depression outcomes.

4.3 Results: Does a higher prevalence of risk factors explain higher rates of depression?

4.3.1 *Risk factors for depression*

Major known risk factors for depression in this population include younger age; poorly controlled physical symptoms such as pain; past history of depression; reduced functional status; and inadequate social support (Potash & Breitbart 2002, Wilson et al. 2000). Some tumour types have been associated with greater risks of depression, for example pancreatic cancer; whilst metabolic disturbance resulting from both tumours and treatment effects are also associated with risk of depression (ibid). The link with gender is complicated. Some studies have shown depression to be more common in women, as is the case in the general population. However other studies found the opposite, suggesting that depression in these cancer patients may be in some way qualitatively different from that in the physically well population (Wilson et al. 2000).

4.3.2 *Risk factor distribution in identified studies*

Given the reported links between risk factors and depression, I hypothesised that studies identifying higher prevalence of depression would be more likely to have participants with a greater burden of factors associated with high risk of depression - for example, younger, sicker, patients with poor social support and a past history of depression. In order to test this, I ranked the identified studies according to their prevalence estimate, and examined the relative distribution of reported risk factors (see Table 4.2: the study reference is that defined in Table 4.1).

Studies with a higher prevalence of risk factors for depression (relative to other studies in this review) are shown in red. Moderate risk is indicated in orange and low risk in yellow. Thus for gender, most study samples were 40-60% male. Those with a higher proportion of male participants were marked as moderate risk (in orange). For age, studies with the lowest mean age were identified as highest risk (in red). Physical symptoms were rated for risk based on the relative burden. For example in study B (Minagawa et al. 1996), 79% of people reported mild or no pain; whereas in study A (Hardman et al. 1989), 60% reported moderate-severe physical symptoms. Therefore B is shown as 'low risk' for physical symptoms; A is shown as 'high risk'. Weighting for organic disorder and education are described in section 4.3.4. Social support was ranked according to the relative effects in different studies. Education was used as a proxy for socioeconomic status, with higher levels of education assumed to be associated with better financial status. Therefore higher levels of education were marked in yellow; limited education experience in red. Overall, I expected to see a clustering of yellow at the top of the table (the low prevalence studies), and of red at the bottom with high prevalence studies. Table 4.2 reveals that the issue is more complex.

Table 4.2: Distribution of risk factors across 19 depression prevalence studies: showing High (🟥), Moderate (🟧), and Low (🟨) risk

*Study ref.	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S
Prevalence (%)	3.2	3.2	4.1	4.7	5	6.7	8	9.2	13	16	16	17	18	19.6	22	25	26	41	42
Gender				🟧		🟧				🟧									
Age	🟥						🟨	🟨							🟧				🟧
Physical symptoms	🟥	🟨		🟧	🟥	🟧	🟧					🟨		🟥				🟥	🟥
Function		🟥		🟨		🟨	🟥				🟥			🟥		🟥		🟥	🟧
Organic disorder		🟨	🟨	🟨		🟨						🟨					🟥		
Social support				🟨		🟨	🟥							🟨					🟨
Education				🟥		🟧	🟥				🟨	🟨							🟨

(* Study references: see Table 4.1)

The weighted mean prevalence of depression across the 18 palliative care studies was 21.5%. By comparison, the reported UK prevalence of depression in the Meltzer study was 2.1% (Meltzer et al. 1995); and in the ODIN study was 7.8% in Liverpool, and 6.7% in a global European sample (Ayuso-Mateous et al. 2001). Table 4.2 lists multi-national studies and is not directly comparable to any one country's prevalence. However the weighted mean of 21.5% is so much higher than previous estimates that it suggests the prevalence of depression is greater in people with terminal cancer than in the general population.

The most striking finding from this review was arguably the paucity with which information on risk factors is adequately collected or reported in each study. In part this reflects the heterogeneity of study aims. A number of studies specifically investigated the association of depression with other psychological concerns such as desire for death; individual risk factors for depression were of less concern. Others, including mine, were primarily concerned with highlighting the burden (prevalence) of depression in a population, rather than identifying the cause. With treatment options, especially pharmacological agents, not dependent on causal factors this is perhaps not surprising. In addition, the practical difficulties of measuring multiple variables in sick populations may underpin a pragmatic focus on prevalence rather than causal factors.

Looking at Table 4.2, certainly some studies with 'high risk' populations (such as Brown et al. (1986), Bukberg et al. (1984), and Walsh et al. (2000) with high levels of physical symptoms and poor function were found where they might be expected - at the top end of the prevalence spectrum. However it was also noted that factors reported to be associated with higher rates of depression (in red) are found in studies with an overall low prevalence finding, and vice versa. This implies that overall prevalence may be linked to a complex interaction of risk factors, with the need for larger scale studies and/or meta-analysis to unpick their relative contributions. However examination of existing studies did raise some interesting points, with support for some existing hypotheses but also suggestions for new research focus.

4.3.3 *Support for existing hypotheses with regard to risk factors*

The review supported previous work highlighting age, physical symptoms, performance status, social support, past history of depression and existential concerns as risk factors for depression. (The latter two are described below though not included in Table 4.2). There were still some discrepancies, which are also highlighted and discussed below.

Age

Most studies reported a mean age of sample participants between 60 and 70 years (as might be expected given the demographics of cancer). Previous work suggests depression is more common in younger people; Bukberg et al. (1984) and Lloyd-Williams & Friedman's (2001) findings were consistent with this. Akechi et al. (2004) also reported a sub-group analysis with mean age being younger in those with anxiety or depression (57 years versus 62 years in those with no mental illness, p=0.003). However Hardman et al.'s study (1989) involved a relatively young population but still reported the lowest overall depression prevalence.

Physical symptoms

The low prevalence of depression in Hardman et al.'s study (1989) is additionally surprising given the high reported prevalence of physical symptoms. However, sub-group analysis revealed that 41% of people with self-reported moderate to severe physical illness had a psychiatric disorder (including depression) compared with only 10% of patients who felt well. The apparent discrepancy may therefore have arisen from a failure to recognise the heterogeneity of individual study samples. Akechi et al's (2004) sub-group analysis also supported previous research in identifying increased pain in those with anxiety or depression compared with those who were psychologically well. Yet there still appear to be people with high levels of physical symptoms who do not get depressed (for example, the 10% in Hardman et al. 1989). This suggests that physical symptoms *alone* cannot explain the higher rates of depression generally seen in studies of cancer patients but may play a contributory role in a (likely complex) interaction.

Past psychiatric history

Several studies provided support for past psychiatric history as a risk factor for depression. In Hardman et al.'s study (1989), people with a current psychiatric disorder were more likely to have a history of treatment for 'nerves' (17%) than those without a mental illness (3%). Akechi et al. (2004) reported that past history of major depression was 11% in those with no anxiety/depression versus 28% in those with active anxiety/depression ($p<0.005$). Breitbart et al. (2000) reported a moderately high depression prevalence of 17% and noted that 32% of his sample had had previous psychiatric treatment.

Performance status and Function

The correlation between performance status and depression prevalence appeared to fit the expected pattern with significant functional impairment seen in studies with a higher prevalence of depression and vice versa. Minagawa et al. (1996) was the exception with the mean Karnovsky score for the sample indicating significant disability whilst the overall prevalence of depression was low at 3.2%. However his study also reported low levels of pain. It may be that pain is a confounding factor in studies with high impairment linked to high depression rates. Minagawa et al. (1996) also excluded patients with an organic cause for mental health problems from his sample (by using the Mini Mental State Examination as a screening tool). Organic disorder (and/or cognitive impairment) could therefore be a confounding factor in studies showing links between impairment and depression.

A better indication of the link between performance status and depression is seen in those studies which compared function in depressed and non-depressed sub-groups. Akechi et al. (2002) reported that lower performance status was associated with psychological distress ($p=0.002$). However there was no association between depression and pain, which does not support the suggestion of pain as a confounding factor in the association between performance and depression. In a later study, Akechi et al. (2004) found that performance status was statistically significantly lower ($p<0.005$) in people with anxiety/depression (mean Karnovsky score = 66: indicates the need for occasional assistance) than those without (mean Karnovsky score = 76: indicates able to self care). Bukberg et al. (1984) reported that 77% of people with poor function status were depressed; 57% with moderate functional status were depressed; and only 23% were depressed who had good functional status. His study suggests a dose-response relationship, adding strength to the hypothesis of a causal relationship between performance status and depression. However Breitbart et al. (2000) reported no association between Karnovsky score and depression. The cross-sectional nature of existing studies limits the ability to distinguish confounding and causal relationships.

Social support

Social support has been suggested to have a protective effect in the development of depression in this patient group. In this review, studies reporting high levels of social support were found at both ends of the depression spectrum. Akechi et al. (2002, 2004) reported high levels of social support in samples with a low overall burden of depression. However other risk factors were also favourable in his studies. In studies with high levels of depression, the effects of high levels of reported social support appear to have been unable to compensate for the high levels of physical symptoms and functional impairment seen in, for example, Radbruch et al. (2003) and Bukberg et al. (1984). Many studies reported marital status as a proxy for social support, arguably reflecting previous observations in non-terminal populations of a protective effect of marriage, at least for men. The protective effect of marriage has been presumed to arise from social support factors. However Hughes (1985) revealed that in the 72% of the sample who were married, 12% reported that their spouse was very distressed by their illness. Thus in the setting of people with terminal cancer, the effects of marriage on mental health may not be the same as in the general population; marriage cannot be assumed to equate with the beneficial effects of good social support. In addition Chochinov et al. (1995) reported low levels of depression in a sample in which 47% lived alone. Thus living with someone may be considered a crude measure of social support.

Existential concerns

Existential concerns were not generally measured by most studies. However Akechi et al. (2004) noted that concerns about being a burden, and loss of independence and dignity were all associated with anxiety and depression. In a review of depression in people with terminal illness. Noyes (1990) reported that existential concerns and loss of meaning were better predictors of depression scores than other factors such as physical symptoms. However, it was not clear whether existential concerns were cause or consequence of depression, or a confounding factor skewing depression estimates. The nature and extent of this association certainly needs greater investigation.

4.3.4 *New ideas arising*

The previous discussion highlights the inconsistencies apparent from a review of risk factors across the studies. However two factors stand out from Table 4.2 as warranting further consideration given an apparently consistent link between level of risk and prevalence of depression: namely organic disorder and educational status.

Organic disorder

A high prevalence of depression in a study sample equates to a significant proportion having had symptoms indicative of depression. Difficulties with distinguishing symptoms of depression from physical effects of cancer and its treatment are discussed in section 4.5.1, starting p63. However, depressive symptoms may also be caused by organic processes: physical effects on the central nervous system which account for the presence of mood-related symptoms and may therefore be mistaken for depression. A clinical diagnosis of depression can only be made if an organic cause (organic disorder) has been excluded (World Health Organisation 1992). Thus organic disorder cannot, by definition, cause depression; however it may be a confounding factor in depression measurement.

Organic disorder may be the result of factors unrelated to cancer such as cognitive decline associated with age; or related to the cancer as a result of the tumour or metastases, medical treatment including chemotherapy, or part of an involutional decline associated with the dying process. Organic disorder may therefore be a confounding factor in depression studies which reported a high prevalence of depression (and depressive symptoms), particularly those with very unwell populations who are close to death.

Only some studies considered organic disorder as a potential confounding variable in the measurement of depression; the Mini Mental State Examination was used to assess cognitive function (Akechi et al. 2002; Akechi et al. 2004; Breitbart et al.

2000; Minagawa et al. 1996; Power et al. 1993). Those with low scores were considered to potentially have an organic brain disorder causing their mood symptoms rather than a primary diagnosis of depression. Studies which excluded patients with organic causes for mental health symptoms (in yellow in Table 4.2) identified lower levels of depression in their samples, suggesting that organic disorder may have been a confounding factor in explaining the higher prevalence identified in other studies. Further evidence of this is seen in Power et al's study (1993) where high levels of cognitive impairment were reported in a sample which also had a relatively high prevalence of depression.

Organic decline in brain function (and possible resulting altered mood) may be part of the natural process of dying. Time to death may therefore be associated with organic decline, and act as a further confounding variable in studies of depression prevalence. For example, Lloyd-Williams & Friedman (2001) reported a mean survival time of 32.2 days for their sample, 22% of whom had depression; whilst Radbruch et al. (2003) reported a prevalence of 19.6% in a case review of 1304 patients, 41% of whom died during that admission. Minagawa et al. (1996) reported a low mean survival time of 54.7 days but with a low depression prevalence of 3.2%; however, he excluded those with organic disorder from the study. A link between time to death, organic decline and depression may also help to explain the low levels of depression identified in my study compared with previous published studies. Non-responders in my study were more likely to be closer to death (see Chapter 3); those in the final sample may therefore represent a 'fitter' population than those identified in previous studies in palliative care settings. Only 18.6% of my sample died within six months of the study. However, it may also be the case that depression causes a decline in cognitive function. The direction of any causal relationship needs further investigation through the use of longitudinal studies.

The observed association between organic decline and depression may have also been an artefact. 96% of the sample from Power et al.'s study (1993) died during the study period or within six months; his results revealed both high levels of organic disorder and a high prevalence of depression. However sub-group analysis revealed that whilst cognitive function was inversely correlated with days to death, it did not correlate with depression score. The association therefore requires further study to determine its nature and significance.

Educational status

The role of educational status in predicting the prevalence of depression in a study sample also requires further attention. Education status is a predictor of health status, partly through its association with socioeconomic status (SES). In the general population, depression is reported to be higher in lower socioeconomic groups, which would generally be those with lower educational status. However in this review higher social status (with a probability of higher educational status - shown in yellow) was associated with greater levels of depression; poorer educational attainment (shown in red in Table 4.2) was associated with lower depression. Akechi et al. (2004) reported that 33% of the sub-group without anxiety/depression had less than nine years of education compared with 17% in the group with anxiety and depression (p=0.03). Social support may have been a confounding factor in this observation with, for example, better social support networks associated with lower SES.

These observations also raised concerns about measurement artefact. Diagnosis of depression relies on a two-way communication between patient and doctor (or researcher). Patients and clinicians may both interpret questions/answers differently from the way they were intended, particularly if they come from different socio-cultural backgrounds. Researchers have also raised concerns about response tendencies' bias: a process in which personal attributes introduce variation in replies to questions that may not be related to the phenomenon under investigation (Vernon et al. 1982). One such source of bias is social desirability response: the likelihood that a person gives an answer they believe to be socially appropriate, rather than a true reflection of actual experience (ibid). In a study of patients with chronic pain, Deshields et al. (1995) reported that patients with greater social desirability response bias reported less depression (with the Beck Depression Inventory – a self report, screening tool). No work has yet been done in the palliative care setting to investigate the role of response bias in assessment of depression with screening tools or diagnostic interviews.

4.3.4 *Summary*

Differences in risk factors may explain, at least in part, the observed variability in prevalence estimates. However the effects appeared to be the result of complex interactions between risk factors. Differentiating causation, consequence and confounding would require statistical modelling of larger, longitudinal studies.

Two risk factors stood out as potential confounding factors in the studies of depression prevalence: organic decline and educational status. The confounding effects of organic decline may explain the higher prevalence of depression noted in palliative care studies (generally involving patients closer to death) than in my primary care study (where patients' survival was better). Educational status may be a proxy for perhaps social support or psychological coping; but also raises the possibility of measurement artefact. Variability in depression estimates may therefore be the result of both risk factor distribution, but also measurement artefact and confounding factors within different study populations. Greater understanding of these effects is necessary to improve the utility of the depression model in understanding patient need in this population.

4.5 Measurement of depression: further problems of artefact

This review and the findings in Chapter 3 have raised concerns about confounding and measurement artefact in depression research. The findings led me to question how far variability in depression estimates is an artefactual effect of measurement processes, and therefore extent to which we can and should base treatment and management decisions on these data. I therefore turned to consider how we measure depression, starting with a consideration of how we define it.

4.5.1 *Researching depression: Defining depression*

Depression is defined or diagnosed on the basis of identification of a cluster of symptoms which clinical observation and theory predict equates to a shared underlying pathology (Goodwin & Ghaemi 2000). Classification of mental health symptom clusters into pathology-based disease entities is listed in the two main classifications of mental illness in use today: the International Classification of Disease version 10, ICD-10 (World Health Organisation 1992) and the Diagnostic and Symptoms Manual version IV, DSM-IV (American Psychiatric Association

1995). Depression is defined as the presence of a set of symptoms of which depressed mood and loss of interest are at the core (see Box 4.1: from Bech 2000). The number and duration of symptoms determine the severity of the depression (ibid). Whilst the individual symptoms identified in Box 4.1 may be found in other mental and physical disorders, it is the clustering of symptoms which leads to the diagnosis of depression. However, in a study of over 1500 people using both the ICD-10 and DSM-IV classifications, Andrews et al. (1999) reported a concordance of only 83% in diagnosis of a depressive episode. Thus there is room for further development of the description of, and diagnostic criteria for, depression.

Box 4.1: Symptoms of depression (Bech, 2000)

Core symptoms

- Depressed mood most of the day, nearly every day
- Markedly diminished interest or pleasure in all/almost all activities most of the day, nearly every day
- Loss of energy or fatigue nearly every day

Additional symptoms

- Loss of confidence or self-esteem (ICD-10 only)
- Unreasonable feelings of self-reproach or excessive/inappropriate guilt, nearly every day
- Recurrent thoughts of death or suicide, or any suicidal behaviour
- Diminished ability to think or concentrate, or indecisiveness, nearly every day
- Psychomotor agitation or retardation nearly every day
- Insomnia or hypersomnia nearly every day
- Change in appetite (decrease or increase with corresponding weight change)

Defining depression in terminally ill or physically ill patients is more complex. Many of the physical symptoms listed in Box 4.1 are biological effects of cancer as well as symptoms of depression. Behaviour that might be considered to indicate depression in a physically well individual may be appropriate in someone facing death; for example disengagement from previous areas of interest is a common experience (Wilson et al. 2000). A number of changes to the definition have been suggested to improve diagnosis of depression in physically ill populations, including development of new diagnostic criteria (for example, the Research Diagnostic Criteria: Spitzer et al. 1978) and adjustments to the existing criteria for use in physically unwell populations (for example, the Endicott criteria: Endicott 1984). However although several studies have demonstrated that altered criteria affect measured depression rates (with the lowest rates seen in studies using the strictest criteria), there is no consensus regarding an optimal approach (Stiefel et al. 2001).

4.5.2 *Researching depression: measuring depression*

Diagnosis of depression traditionally relies on a dialogue between patient and doctor to determine the presence or absence of the symptoms listed in Box 4.1. The inherent variability in that process is unacceptable in a research setting and led to the development of standardised diagnostic interview schedules such as the Structured Clinical Interview Schedule for DSM-IV, SCID (First et al. 2004), Present State Examination, PSE (Wing 1976), and the Schedule for Affective Disorder & Schizophrenia, SADS (Endicott & Spitzer 1978). These standardised diagnostic interview schedules improve repeatability in the measurement of depression (Wilson et al. 2000). Symptoms are then assessed against the diagnostic criteria discussed in 3.5.1. To date, there is no evidence to support one over the other (Stiefel et al. 2001). However, given the previously identified concerns over the definition of depression, whilst each tool can identify the presence or absence of a set of symptoms, whether they are 'truly' measuring the presence of depression is less clear.

4.5.3 *Reviewing the studies: measurement processes*

There is no single gold standard approach for measuring depression in this patient group. I therefore compared the methodological processes used in different prevalence studies in order to assess the extent to which they may explain variability in depression prevalence estimates. In light of the discussion above, I looked at a number of variables:

- the study setting (inpatient versus outpatient), since Chapter 3 raised concerns that measurement tools may work differently in different settings;

- Sample size: imprecision has been raised as a problem in the discussions so far. I considered whether sample size predicts higher or lower depression estimates;
- Classification of depression used: DSM and ICD definitions do not invariably result in the same diagnosis of all patients assessed for depression. I looked for evidence that the classification system used is associated with depression estimate;
- Tool: A number of tools have been validated for use in depression research, including that in a palliative care setting. However not all studies used a validated tool. In addition, there is still a debate on which diagnostic criteria are most appropriate for use in a population with terminal illness (Wilson et al. 2000). I therefore assessed whether the measurement tool and diagnostic criteria used were associated with identified depression outcome.

A summary of these factors for each of the identified studies is shown in Table 4.3. Again, the risk status was assessed relative to other studies. Studies with a response rate lower than mine (48%) are flagged in red as indicating risk of 'low quality'. I am not suggesting that my response rate was ideal. I simply wanted to see if response rate might explain the lower prevalence identified in my study compared with others. Low quality is therefore a relative term. Sample size is treated in the same way, with studies smaller than mine (n=70) highlighted in red. Studies using a non-validated diagnostic tool, or non-standard diagnostic criteria are highlighted as low quality (in red). In all cases, these authors developed their own tools and criteria, as indicated in Table 4.3 and described in more detail in Table 4.1.

Table 4.3: Sampling and measurement factors across 19 depression prevalence studies: showing the distribution of low quality (🟥) indices

Study ref.	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S
Prevalence (%)	3.2	3.2	4.1	4.7	5	6.7	8	9.2	13	16	16	17	18	19.6	22	25	26	41	42
Response rate (%)	🟥 NR	85	48	80	🟥 40	🟥 27	🟥 26	🟥 26	100	🟥 NR	73	59.7	🟥 28	100	63	🟥 15	90	100	69
Sample size	126	93	70	129	🟥 59	209	199	130	224	🟥 50	🟥 44	92	79	1304	100	🟥 44	81	1000	62
Diagnostic Tool										🟥 Own								🟥 Own	
Diagnostic Criteria														🟥 Own		🟥 Own		🟥 Own	

Key for Table 4.3:

Study reference = reference assigned in Table 4.1

NR = not recorded

'Own' = developed and used own diagnostic tool and/or criteria

As previously noted, there was considerable methodological heterogeneity across the studies. Sample sizes varied widely - between 44 and 1304. The two largest studies (Radbruch et al. 2003, Walsh et al. 2000) were at the high end of the prevalence spectrum, but the high level of risk factors (presence of physical symptoms, functional impairment and poor prognosis) in these populations has already been highlighted. Studies of inpatients revealed both high and low estimates of depression prevalence: setting does not appear to correlate directly with outcome.

Response rate or inclusion rate was not always reported. Studies with 100% response rate involved data extraction from standard clinical admission protocols (Durkin et al. 2003, Radbruch et al. 2003, Walsh et al. 2000). No correlation between response rate and prevalence was observed (Pearson's r=0.31, p=0.23).

The classification systems used varied across the studies. Five studies defined depression using ICD criteria, nine used DSM, three used the Research Diagnostic Criteria and two used their own classification based on symptoms identified in Box 4.1 (see Table 4.1 for references). ICD and DSM criteria were used in studies reporting both high and low prevalence. However the studies using their own classification both identified higher burden of depression. In particular, Walsh et al. (2000) undertook the largest study but used his own definition of depression and measurement tool for assessing it. Measurement error may therefore have played a significant but unquantifiable role in explaining the very high levels of depression noted. Certainly reviews have previously noted that the more rigorously defined the notion of depression in a study, the lower the prevalence estimate (Potash & Breitbart 2002, Wilson et al 2000).

With regards to measurement tools, ten studies used validated diagnostic interview schedules, five used standard clinical history taking, and three developed their own tools (see Table 4.3 and further details in Table 4.1). Eight studies had more than one clinician conducting diagnostic interviews, but only one reported inter-rater reliability. Those studies using their own tools reported prevalence estimates at the high end of the range (19-41% in Brown et al. 1986, Radbruch et al. 2003, Walsh et al. 2000). Just as less rigorous definitions of depression have been associated with higher prevalence estimates, the same may be found when using non-validated measurement tools. However even where validated tools are used, my previous discussion about educational status and the effects of interpersonal factors on response to questioning may be important. Thus the possibility of significant measurement error in many of the estimates could not be excluded, but also could not be quantified.

Finally, the depression burden identified in Tables 4.2 and 4.3 was based on cross-sectional assessments of depression. In two studies, follow-up data were also available. Akechi et al. (2002) followed up patients at six months and noted that all four cases of baseline depression had resolved, but three new cases developed. At six months follow-up in Hughes study (1985), of thirteen cases identified at base-line eight had recovered and five stayed depressed. Three new cases of depression were also identified. Cross-sectional studies can only give us a snap-shot in time and do not give a full indication of need.

4.6 Discussion

4.6.1 *Reviewing the review*

The implications of this review are only of interest if the findings can be considered to be trustworthy. The methodology used, although novel in parts, included several aspects described within the systematic review literature (Higgens & Green 2006). The search strategy used to identify studies followed many of the requirements of a systematic review. Unfortunately I was unable to follow up the grey literature and look for unpublished studies given the constraints of time and resources. Publication bias may be a problem in this area, although was not identified as significant by Stiefel et al. (2001) in their review. All studies meeting the inclusion criteria were included in the review, with no exclusion of studies based on assessment of study quality. Including a systematic scoring of study quality could have supported a more explicit statement on the "strength of the evidence" (Higgens & Green 2006: 168). However my primary goal in this review was not to identify the 'true' prevalence of depression in palliative care populations, but to explore the extent to which observed variations were due to measurement artefact or real differences between samples. Finally any systematic review requires interpretation and judgement of study quality and results. Usually, this would be done by a research team with explicit mechanisms for dealing with discrepancies and disagreement. A similar team approach to discussing and defining the high, moderate, and low risk status ascribed to studies in Tables 4.2 and 4.3 could have added weight to the analysis presented in my review.

My review raises doubts over the 'truth' of the knowledge identified from the literature. However in this thesis, I am seeking to judge knowledge against the criteria of a subtle realist stance, looking beyond the question of 'true' or 'false'. I therefore applied the criteria identified by Maxwell (2002: see Chapter 1, p6) to this review and identified concerns related to all five criteria. Descriptive validity requires a clear and accurate recording of the research process. There were variable standards of reporting in the studies, especially in relation to sampling issues and diagnostic criteria and particularly in those studies which developed their own. Interpretive validity requires an assessment of how accurately the interpretation reflects individual perspectives. The methodology used in these studies did not seek to identify people's own assessment of need and I have raised concerns that survey responses may not always reflect the 'true' experiences of individuals, for example as a result of social desirability response.

Doubts over the theoretical validity, how well the account serves as an interpretation and explanation, have been raised given the uncertainties associated with the conception of, and diagnostic process related to, a pathology of depression. Massie (2004) highlighted the need for identification of biological markers of depression to address this concern.

Whilst the survey methodology used may raise concerns about interpretive validity, the objectivity and use of statistical methodology is supportive of generalisability. However results can only be generalised to people with the same characteristics as the sample. A comparison of my study with those previously reported indicated that results from palliative care may not automatically be transferred to primary care. I have also highlighted the heterogeneity of the various samples and suggested that complex interactions between risk factors may be important. Defining the population to whom results can be generalised is difficult.

Finally, evaluative validity questions the utility of the knowledge. Clearly previous studies have highlighted the potential utility of a biomedical pathological approach through demonstrating apparent improvements in depression scores with treatment (Stiefel et al. 2000). In my review, I have raised concerns about the validity of depression scores and what they actually mean. It is unclear whether a reduction in depression score equates to something meaningful for patients, I would therefore propose that future studies should assess the effects of treatment using a different outcome measure, such as a quality of life or well-being tool.

4.6.2 *Implications of the review*

In Chapters 3 and 4, I have explored the potential applicability of a palliative care knowledge base in informing primary care practice. I have identified concerns that a primary care specific evidence base is needed. However I have also highlighted the need to better explain variability in existing research findings, notably the effects of confounding factors and measurement artefact, in order to be able to judge the knowledge arising from research studies.

Variation in the presence of risk factors for depression in people with terminal illness may account for some of the observed variability in prevalence estimates and hence the differences identified in primary care and palliative care studies. There was a suggestion of complex interactions between variables, with some (for example, social support) acting as protective agents compensating for the negative impact of, for example, physical impairment. Larger studies (or pooling of standardised smaller studies) are needed with statistical modelling to better understand the complexity of depression in terminal cancer populations and thus support the application of findings in clinical practice.

However there was also a suggestion of significant problems with the research process: that observed associations between some risk factors and depression may result from measurement artefact rather than real differences. Given the cross-sectional nature of most studies to date, it is hard to distinguish between causation, association and confounding. My review questioned whether clusters of symptoms normally ascribed to a pathological state of depression may instead be explained by other processes such as involution and dying in this patient group. For example, organic disorder (as part of involutional decline) may cause depression and thus account for higher rates of depression seen in palliative care populations, who are also more likely to be closer to death. However organic disorder may also be a confounding factor in the measurement of depression since both depression and organic disorder may cause depressive symptoms. The cross sectional nature of the existing studies make it impossible to determine which is causing the symptoms and thus to distinguish causation from confounding.

4.6.3 *Future research and clinical practice*

There are significant implications for clinical practice. Interventions designed to reverse symptoms which are presumed to indicate depression may interfere with a natural process of involution and 'shutting down' with a risk of negative consequences. Difficulty in distinguishing cause, association and confounding in the development of depressive symptoms limits our ability to develop protective approaches or interventions

Assuming that the pathological model of depression is in some way right, or useful, limitations to our understanding of the nature of the pathology appear to underpin many of the deficiencies highlighted in this review. Greater understanding of the underlying pathology of depression may help in the development of more precise diagnostic tools (ideally incorporating biological markers (Massie 2004)), and also potentially new therapeutic options. However current limitations in understanding of pathological mechanisms should not delay research which can help with the application of existing findings to inform clinical practice.

Large scale longitudinal studies could contribute to better understanding of the interrelationship between depressive symptoms and explanatory variables, distinguishing causation from confounding. Causal factors might include depression, organic decline, physical discomfort, social problems, and existential concerns. Confounding factors could include organic disorder, a measure of social desirability response, and time (survival time or time to death). Statistical modelling of longitudinal data could assist in development of improved diagnostic indices which better predict the presence of pathology.

Research efforts could focus on identifying the utility (benefits and risks to individuals) of interventions for treating symptom clusters, rather than focusing on measuring presumed pathological change (e.g. prevalence of 'depression' and change in depression scores with treatment). This could be achieved through developing a prognostic index: identifying factors which predict benefit from interventions (including antidepressants), again through the use of longitudinal studies. Concerns over the validity of assessment of depression could be accommodated by using other outcome measures; perhaps a global assessment of wellbeing or quality of life. The aim would be to develop a multi-dimensional prognostic index, which would include both depression symptom and risk factor scores, to predict who is most likely to benefit (or not benefit) from antidepressants or other therapeutic interventions.

Finally with concerns raised about the validity of current measurement tools for depression (and even perhaps its validity as a concept), I would propose the need for greater research into the risks of a diagnosis of depression. Both pharmacological and psychological therapies are advocated for treatment of depression in terminally ill cancer patients, but both derive from the perceived need to correct a pathological state. Whilst something is known about the side effects of antidepressants, I am concerned that little is known about the effects of incorrect diagnosis (with or without treatment) for example in the case of organic decline. Attempts to treat and reverse a natural involutional process, in the mistaken belief it is depression, could have adverse consequences for patients.

4.7 Conclusions

This chapter has explored the current biomedical research approaches to understanding depression in this patient group. I have discussed the empirical limitations within current research into depression in people with terminal cancer, and identified some possibilities for research which might help address them. I have also mentioned the theoretical limitations in describing and defining a pathological state of depression. Pilgrim & Bentall (1999) proposed that these concerns reflect an epistemological problem (how we know about the world) rather than an ontological one (what the reality of that world is). Our failure to adequately understand depression doesn't mean there isn't a 'real disease' that is depression; but reflects the limitations of our research methods at this point in time. Their stance would support increased efforts to develop knowledge within existing research modalities.

Others dispute the existence of a 'true entity' that is depression. The existence of a pathology of depression reflects a *belief* in a shared underlying pathology, rather than a certain knowledge of its existence (Wing 1978); albeit a belief which may have offered utility in clinical practice. I do not seek to provide an answer to this debate in my thesis. Within my subtle realist stance there is no requirement to establish truth. Instead my focus is on a reflexive understanding of knowledge, including a consideration of its utility. Based on the work described in Chapters 3 and 4, I therefore feel there is a greater need to establish the utility of a pathological concept of depression through greater consideration of the risks, as well as the benefits, of diagnosis and treatment.

To fully understand the strengths and weaknesses of a biomedical approach to understanding depression requires an appreciation of alternative perspectives on the emotional experiences which are 'pathologised' by a medical account. In particular, we need to understand how emotional experiences are perceived by the individuals who live with them. In the next chapter, I will therefore review some of these alternative perspectives on understanding emotions and distress. Drawing on this review, I will subsequently describe the development of my study looking at need from the perspective of the individual patient.

Chapter Five: Developing the patient-centred study – aims and methodology

5.1 Introduction

Having explored a biomedical perspective on understanding emotional disturbance, I turn to consider my second stated theoretical approach: an existentialist focus on the lived experience of patients. In order to guide the development of this second part of my study, I began by looking at the growing body of research describing people's lived experiences of cancer and terminal illness. In this chapter, I will review the existing literature and thus describe the development of the aims and methodology for this study.

5.2 Exploring lived experiences

An existential approach emphasising individual authenticity is a core feature of much social science research which seeks to understand the social world of groups and individuals (Ritzer 1992). In reviewing the literature, I identified a body of research which analysed individuals' accounts of illness. This could be broadly divided into two groups. The first sought to understand and develop existing sociological concepts. For example, Fife (2000) used an analysis of people's accounts of living with cancer to develop sociological understanding of the nature and impact of stigma. The second group of studies took individuals' experiential accounts as the primary focus of study, seeking to identify what the structure and form of those accounts tells us about the phenomenon of living with cancer. In reviewing the strengths and weaknesses of both, I was able to identify the approach I would adopt for my study.

5.2.1 *Exploring concepts.*

Sociological theory and research seeks to identify themes or concepts which may help explain the social world, and thus contribute to our ability to live in that world (Ritzer 1992). A number of these core concepts have been applied in research into terminal illness; the result adds to our knowledge of the sociological concept as well as to our understanding of cancer experiences. Concepts identified in the literature included embodiment (Waskul & van der Riet 2002), dignity (Chochinov et al. 2002a, Waskul & van der Riet 2002), stigma (Fife & Wright 2000), resilience (Nakashima & Canda 2005), spirituality (McClain et al. 2003), social causes of health (Wright et al. 2002), and somatisation (Breslau 2003); some of which are discussed briefly below.

Waskul & van der Riet (2002) used the concept of an embodied self and sought to explore the impact of cancer on an individual. Embodiment describes "the identification of an abstract idea with a physical entity" (MacLachlan 2004: 2). Abstract ideas about 'being' and the 'self' can therefore be described in terms of something visible and comprehensible, such as a reference to an embodied self (ibid). Waskul & van der Riet (op cit) therefore explored the impact of cancer on the self through describing people's struggle to deal with 'out of control' bodies, focusing on the difficulties of maintaining dignity. Although their work offered some insights to health care professionals working with people with cancer, the aim was primarily to contribute to broader theoretical advances in understanding the relationship between the body, self and social interactions. It was unclear how their findings could directly influence patient care.

The concept of dignity has been identified as an important moral principle and basic human need, but has not been extensively researched from a patient perspective (Chochinov et al. 2002a). Chochinov et al. (ibid) therefore undertook a study to identify whether the concept of dignity could be useful in supporting development of palliative care services. They began by exploring cancer sufferers' conception of the term, and found that lay accounts of dignity had some overlap with the theoretical concept described in the literature. When asked to describe what dignity meant to them, participants spoke of occasions when dignity had been either maintained or threatened. Importantly, life without dignity was described as "no longer worthy of living" (Chochinov et al. 2002a: 441). The authors therefore proposed that the concept of dignity could be useful in developing a model of care to support the end stages of life. However they also acknowledged that the mechanisms and processes for doing this remained unclear.

The concept of stigma arises from sociological theories of control of deviant behaviour. Stigmatising conditions are ones which "set people apart from normal people, that mark them as socially unacceptable or inferior beings" (Scambler 1997: 173). Fife (2000) compared the effects of stigma in two diseases: HIV/AIDS and cancer; her primary aim was to better understand the breadth and utility of the theory of stigma. Stigma was found to have a significant impact on self esteem and, by implication, emotional state and distress. Similar stigmatising effects and emotional consequences were observed for both HIV/AIDS and cancer patients. Patient experiences and outcomes were determined by societal reactions rather than the disease itself. Like dignity and embodiment, stigma was identified as an important concept in understanding health experiences, and may offer a useful explanation of emotions in cancer patients. However the practical applications in clinical care for all three concepts remain uncertain.

Coping is a commonly used, if poorly defined, theme in sociological accounts of adverse life events and illness experience. Nakashima & Canda (2005) focused on the concept of resiliency as an aspect of coping in a study of hospice patients. Personal resilience was strongly linked to spiritual and psychosocial well-being, and contributed to a good death. McClain et al. (2003) also demonstrated the importance of spiritual well-being in predicting quality of life in people with terminal illness. However once again there are difficulties in translating these concepts into clinical care (McClain et al. 2003).

Overall, these studies provide a detailed account of concepts which all contribute to an understanding of particular aspects of the lived experiences of cancer patients. Focusing on one (usually researcher-defined) idea allows development of depth of understanding. However it limits the utility of the resulting knowledge in informing clinical care of an individual with complex, often interconnecting, needs.

5.1.2 *Exploring narratives*

The second group of studies identified in my review took individuals' accounts of illness as the primary unit of analysis. These narrative-based studies investigated how illness impacts on an individual 'self', however here the focus is on a 'narrative self' (Lieblich et al. 1998) rather than, for example, the embodied self described by Waskul & van der Riet (2002). Various approaches to narrative research were identified within the literature. Some studies focused on accounts at particular disease stages, for example remission or entering a terminal stage. Some looked at the content of stories; others at the structure of stories, and why people told stories in the way they did.

McKenzie & Crouch (2004) took a disease-stage approach to identifying narrative, looking at two people who had survived cancer. They described the ongoing suffering experienced by their participants, largely a result of the sense of change: now being a person who has 'had cancer' and therefore somehow different from others. Similarly, Forss (2004) recounted the disruption described by women who had been told they were at high risk of cervical cancer following a screening test (a cervical smear). Again, the disruption was associated with emotional distress. Navon (2004) looked at the effects of advanced cancer in a study of men with advanced prostate cancer where illness disrupted narrative in two ways. Firstly, men no longer saw themselves as generally 'healthy'. In addition, the side effects of treatment led to feminisation and loss of a sense of being a 'healthy sexual male'. Both contributed to distress.

Narrative research therefore focuses on understanding lived experiences rather than more abstract theoretical sociological concepts. The literature on narrative also resonates with my experiences of clinical practice. It is often the effect of people's illness on their attempts to live their normal lives which prompts them to come and see me as their doctor; an observation confirmed in the work of Zola (1973) and Mechanic (1978). A developing body of research has also identified narrative as a potential approach for clinical intervention: supporting a healing process through the restoration or reconstruction of a life narrative (Greenhalgh & Hurwitz 1998, Launer 2002, Mattingley 1998). Therefore based on my review of the literature, I felt that research focusing on the impact of illness on self-narratives offered the best scope for answering my research question. I undertook a review of the theoretical work underpinning this narrative and approach; and particularly Bury's (1982) account of Biographical Disruption and subsequent critiques. I will first outline the ideas described in that body of work before outlining how I used them in my study.

5.3 The theory of Biographical Disruption: developing my study

In 1982, Bury proposed that chronic illness can be understood as a "disruptive event" (Bury 1982: 168). The effect of illness is to undermine what people take for granted: the structures and knowledge which shape a person's everyday life. The result is a "profound re-thinking of the [individual's] biography and self-concept" (ibid: 169); prompting a need to mobilise "cognitive and material resources" (ibid: 178) in order to deal with the disruption. Thus he argued that illness prompts a search for meaning, striving to restore a disrupted biography. Bury (1982) proposed that people may use medicine as one resource in seeking answers to their questions. However whilst medical knowledge is often useful in the management of physical symptoms, he argued that it has limited capacity to offer explanations for the range of experiences associated with the disruptive effect of illness (Bury 1982). People must therefore identify other sources for explanations: using experiential knowledge or adopting a 'trial and error' reflective process (ibid). Both the disruption and the subsequent search for meaning carry emotional consequences.

Bury's (1982) account usefully focused attention on the effects of illness beyond that of the physical impact; looking at the negative impact on emotions, social lives and individual expectations (Faircloth 2004). Building on his work, others have sought to describe the processes by which people manage the effects of disruption. Williams (1984) identified a process of Narrative Reconstruction: the restoration of meaning following the disruptive effects of illness. In a study of men with HIV/AIDS Carricaburu & Pierret (1995) described how the reconstruction process can lead to Biographical Reinforcement. The disruptive effect of illness prompted a need to reconstruct self-identity, but the process in turn reinforced important elements of the self. This was revealed as a difficult but ultimately positive experience. Most recently, and based on analysis of interviews with people recovering from a stroke, Faircloth (2004) proposed that illness need not be disruptive. Experiences may be integrated into an ongoing life narrative or account of self-identity: so called Biographical Flow.

Thus it is apparent that the impact of illness on narrative varies. A number of factors have been suggested to explain why illness effects differ, including individual factors such as age and co-morbidity, together with wider cultural or social effects. Bury

(1982) proposed that illness is more likely to cause disruptive effects in middle age since it is unexpected, being a problem perceived to link to old age. Time of life mediates the impact of illness. Pound et al. (1998) proposed that pre-existing morbidity may offer a protective effect against disruption. In a study which interviewed people after a stroke, those who had previous experiences of illness (and its disruptive effects) were less likely to suffer significant harm. Radley (1987) focused on the socio-cultural factors which shape the self and therefore mediate the impact of illness. For example, manual unskilled workers who rely on their physical capacity to work may experience greater disruption from a physical illness than someone from a socioeconomic group not reliant on manual labour.

A biographical account of the impact of illness on the self usefully draws attention to the wider impacts of illness on individuals and their social networks. It also offers insights into emotional experiences and emotional distress. Disrupted narratives cause distress; restoration of narrative has the potential to restore emotional wellbeing. The models have been used to describe experience in a number of health settings and certainly there appear to be consistency in accounts which suggest the concepts have usefulness in describing the lived experiences of individuals. Narrative accounts and meaning provide potential for interventions and health care as is reflected in the work of Greenhalgh & Hurwitz (1998), Launer (2002), Mattingley (1998) and others.

However there are still gaps within the literature. In particular there is still a lack of understanding as to why illness is disruptive and problematic for some people, but not others (Williams 2000). Lawton (2003) argued that we need to move away from looking at individual meaning to exploring wider societal and contextual issues: including the effects of illness and disruption on relationships, and the economic and socio-political effects of illness and disruption. To his list, I would add the effects of and on health care systems, including the adequacy of current systems to support biography and the self. For example, Pierret (2003) argued that we need to understand medicine as a cultural system: as both a resource and potential constraint in narrative, meaning and healing. Overall, I would propose that we need to better understand the impact of medical practice on the self, and its role in the process of maintaining or restoring biography.

I opted to use the theoretical accounts of Biographical Disruption to seek to understand emotional experiences in primary care patients with advanced cancer. I sought to focus on the identified gaps in the literature, including the role of health care and health care systems. I aimed to contribute to the growing knowledge base on biography but also answer my research question on how a GP should support a patient with emotional distress.

5.4 The research question

My research question asked: does the impact of illness on life-narratives help understand distress in primary care patients with advanced cancer? Guided by the literature review previously described, I identified the need to collect and analyse individual narrative accounts of experiences of illness. Given the health status of the participants in my study, I opted to focus on spoken narratives, collected through interviews. My objectives are listed in Box 5.1. In the rest of this chapter, I will describe the development of the methodology I used to meet these objectives.

Box 5.1: Objectives for the qualitative study

- To identify a sample of patients with advanced metastatic cancer from GP practices in Liverpool
- To undertake semi-structured interviews to explore the impact of illness on an individual's biography or life-narrative and emotional experiences
- To identify and utilise an appropriate analytical framework
- To make recommendations on the implications for clinical practice and research

5.5 Sampling

I started by identifying a purposive sample of patients, seeking to select individuals who could illustrate the phenomenon I was interested in (Silverman 2000). Since I wished to explore the emotional experiences of living with advanced metastatic cancer, I chose a number of 'parameters' (Silverman, ibid) which would identify a range of cancer patients. I therefore wanted a sample of both men and women, with different tumour types, and across age ranges. I aimed to include those experiencing emotional distress and those who were not (identified by their score on the

Edinburgh Depression Scale, EDS). I had hoped to include people from different ethnic backgrounds to allow for cultural influences on emotional experience. However these population groups are underrepresented in Liverpool; many of the communities are still young and cancer is not a common problem. All patients identified as eligible for the quantitative study described in Chapter two were considered for the qualitative study.

Sampling, data collection and analysis took place in parallel. As the study progressed, I became aware of the low prevalence of depression in the sample identified from GP Practices. I was therefore concerned that I may be missing an important aspect of the experience of emotional distress in people with terminal cancer. I was also aware of emerging themes requiring further exploration. My sampling approach therefore switched to theoretical sampling: seeking to identify participants on theoretical grounds, including deviant cases who could add depth to the emerging analysis. I therefore focused on those with the highest scores on the EDS, and included people who lived alone (as a proxy for poor social support). I was identifying few confirmed cases of depression in my primary care sample, and was concerned that I may be missing an important sub-group. In particular, I was keen to identify patients who were being treated for distress or depression, or presented expressing distress as a primary concern. Potential eligible patients were therefore identified by Professor Mari Lloyd-Williams (MLW) in her palliative care outpatient clinic. Permission was obtained from the individual's GP to approach the patient as required by my ethics approval.

Sampling continued until the emerging analysis demonstrated coherence, as described in section 5.8, p87. Two patients identified as potentially eligible for an interview declined to take part. One gave no reason; the other was too ill. In total, 16 participants were identified from GP Practices in Liverpool; three high risk patients were identified by MLW. A twentieth interview was conducted with a patient identified from a GP Practice, but during the course of the interview, it became apparent that the woman did not have a terminal illness. This interview was therefore excluded from the analysis. Characteristics of the final sample are shown in table 5.1.

Table 5.1: Summary of participants

Reference	Age (yrs)	Sex	Tumour	EDS score	Lives alone	Attends hospice
Albert	84	M	Lung	6	N	N
Ron	67	M	CLL	10	N	N
Helen	66	F	Colon	16	Y	N
Angela	45	F	Ovary	6	N	N
Nora	63	F	Lung	16	Y	N
Mark	45	M	Lung	16	N	Y
Marjorie	61	F	Melanoma	20	N	Y
Jenny	71	F	Lung	17	N	Y
Mary	63	F	Lung	18	Y	N
Linda	54	F	Breast	17	N	N
Peter	62	M	Prostate	12	Y	N
Jim	83	M	Oesoph.	12	Y	N
Pat	64	F	Lung	12	N	N
Bob	47	M	lung	5	N	N
Ruth	70	F	Colon	7	Y	N
Stuart	48	M	Sarcoma	*	N	Y
Joyce	80	F	Breast	*	N	Y
Joan	55	F	Breast	*	N	Y
John	68	M	Prostate	*	N	Y

Key:

* selected as high risk/expressing distress by MLW

EDS (Edinburgh Depression Scale) scores shown in red indicate high risk scores

Participant highlighted in blue had a confirmed ICD diagnosis of depression

Reference names are not the participant's real names

M = male, F = female; N = no, Y = yes

5.6 Data collection

Data collection was through the use of semi-structured interviews. The venue for all interviews was chosen by participants; all chose their own home. Participants had all received a copy of the Participant Information Leaflet (appendix A3) before deciding whether to take part in the study. Based on the information in that document, all participants were aware that the study was interested in finding out about how they were feeling. They were also informed that I was a local GP and would be conducting the interviews, and that interviews would be tape recorded. The implications of choosing to present myself as a GP rather than a non-clinical researcher are discussed in section 9.3, p164. All participants were contacted by telephone prior to the interview to confirm arrangements and answer any outstanding questions.

Legard et al. (2003) describe the interview as consisting of a number of stages: arrival; introducing the research; beginning and during the interview; ending the interview; and after the interview. In the case of my study, most of the introduction had taken place before the date of the interview as described above. Most of my interviews started almost immediately on my arrival at the participant's house, sometimes before I had set up the recording equipment. My experiences seem to differ from those described by other qualitative researchers in the Division of Primary Care at Liverpool (personal communication, Qualitative Research Network discussions, University of Liverpool). My peers and colleagues describe often spending up to half an hour chatting with participants in order to relax both researcher and interviewee, and to seek to establish a rapport. The difference in my research may reflect people's awareness that I was a GP, with interviews starting quickly in the way a consultation or home visit would. Often the sociable chatting would take place after the interview, over a cup of tea. The latter was not recorded, but field-notes were made immediately afterwards.

Where interviews were commenced by me, I started by asking people how they were feeling at the moment. Follow-up questions were guided by participants' responses and the interview schedule. The first draft of this schedule (appendix A6) was developed based on the literature review and discussion with my supervisors. I aimed to cover topics of relevance to the study objectives. The ordering of questions in the guide was not intended for use in the interview. Whilst I aimed to cover the identified topics with each individual, the detailed wording and ordering of questions was dictated by the individual responses from participants. The schedule was reviewed and updated in light of emerging themes from initial interviews (appendix A6).

Interviews were recorded using a minidisk, transferred to tape (for ease of handling), and then transcribed by me. Tapes were transcribed as soon as possible after the interview and in all cases within three weeks. Through careful listening to the tapes, I recorded the entire interview verbatim. Transcription aimed to capture the content of the interview narrative; pauses or stresses which contributed to the meaning of the story were marked. However I did not seek to produce a detailed record of the structure of the interview narrative, recording all pauses and non-narrative aspects as would be required, for example, in a discourse analysis. The transcription process often prompted personal reflections: memories of events at the time of interview, or new thoughts. These were recorded at the time of transcription, but clearly marked as additional field notes or comments from myself made after the event. For example, where the transcribed text did not reflect the mood of the voice on the tape, or my memory of visual clues, I noted the inconsistencies.

In two interviews, the recording equipment failed. Nora's interview was interrupted by a telephone call after half an hour. In pausing the recorder at this time, the data was accidentally wiped. When Nora asked to continue the interview after the call, I was able to recap on some of the areas covered. I also made field notes on the earlier topics immediately on leaving her house. In the case of Bob, the entire interview was lost since the recording failure was only noted on return to the office. Field notes were made immediately on discovery of the problems, but with approximately an hour delay. However some data were available for analysis from both interviews.

Field notes were collected during and after the recorded interview, noting contextual information as well as additional comments from participants made after the tape recorder was switched off. A research diary was kept throughout the period of the study recording my reflections on the research process, the analysis and comments back from audiences to which the interim findings were presented.

5.7 Data analysis: methodology

My sampling and data collection aimed to produce a rich data set of individual narratives focusing on illness experiences and emotional consequences. Within qualitative research, there are several analytical processes which could have been used to make sense of my data set. These approaches were usefully reviewed by Tesch (1990), who proposed that they could be categorised according to the primary focus of the research. She identified four areas of research interest: the characteristics of language, the discovery of regularities, the comprehension of the meaning of text or action, and reflection; and identified methodological approaches suitable to each.

The first - characteristics of language - includes the narrative methodologies commonly used in the research highlighted in my earlier literature review. These methodologies focus on language as a form of communication; looking at the *content* of language and narrative (content analysis), or the *process* of communication and how people present themselves to others (for example, discourse analysis) (Tesch 1990). Both approaches could offer information of interest to a GP in the care of distressed patients. Understanding how people present their stories could be useful to inform understanding of the clinical interview. A descriptive account of the content of stories could add to GP awareness of the experience of illness.

However I was keen to move from a descriptive account to a more analytical account. As identified in section 5.3 (page 79), I was interested in why people have different experiences of illness, and also in looking at the impact of medicine and health care on that experience. My focus was therefore not so much on the meaning of text (or narratives) per se, but in using narrative data as a tool to explore commonalities and discordance in order to better understand illness experience. In particular, I was interested in Tesch's (1990) second identified category, where the primary research interest is in discerning patterns and conceptualising difference. The relevant methodological approach identified for this was phenomenography (ibid).

Phenomenography is a method that seeks to understand how things work (Tesch 1990), through exploring why people conceptualise or experience phenomena differently (Marton 1997). It assumes that there is a limited number of ways in which they experience a phenomenon (Linder & Marshall 2003). Data collection is through interviews. The researcher must seek to understand how people experience a phenomenon through encouraging the interviewee to "knowingly reflect on their experiences" (Marton 1997: 130). Subsequent analysis seeks to describe and interpret the range of experiences identified within the interview transcripts in order to explain differences (Marton 1986, 1997). The method emphasises individual authenticity, being concerned with how people perceive things, with no reference to what things 'really are' (Marton 1986). It therefore fits within the subtle realist approach adopted for this thesis. The interview narrative is seen as offering an insight into the perceived reality of that person and at that time (Silverman 2000) rather than an absolute truth. The analytical process considers the content of each account from the perspective of the others. It is the relative overlap and difference which offers meaning.

Meaning is therefore sought through an analysis which involves re-reading and familiarisation with the data, leading to identification and coding of statements which represent a single theme or idea. Within and across case comparison enables grouping of statements according to areas of similarity or difference (Marton 1986, Backe 1996).

5.8 Data analysis: method

Although the literature includes a detailed account of the methodology (the theoretical approach) underpinning phenomenography, the methods (the details of how to actually conduct the research) are less well described. Marton's (1986) account describes a general approach to qualitative analysis involving open coding of data to identify emerging themes, with subsequent grouping or categorisation of statements into broader patterns of similarity or difference (Marton 1986, Backe 1996). However I was concerned that my analytical approach needed to be able to consider themes within the context of a broader narrative context. I therefore turned to accounts of descriptive narrative methods in order to identify approaches which might better capture the totality of individual experience in the analysis stage. Lieblich et al. (1998) described two approaches of interest: a holistic-form analysis which focuses on the structure of the narrative, and a holistic-content analysis which focuses on what is revealed by the story. Holistic-form analysis seeks to identify the overall structure and shape of the narrative account. In the case of my study, it could be used, for example, to distinguish Biographical Disruption from Biographical Flow. Holistic-content analysis emphasises the need to understand the meaning of any part of a story within the context of the whole story for that individual. Identification of key themes within individual interview accounts supports subsequent cross-case analysis leading ultimately to an explanatory account of similarity and difference. I therefore opted to incorporate the methods described by Lieblich et al. (1998) within the phenomenographic methodological approach described by Marton (1986) in order to develop an analytical process that met the theoretical requirements of my study.

Analysis followed an iterative process which began once I had done my first interview. My starting point was to seek to identify the effects of illness on individual biography through a holistic-form analysis of the data. Transcripts were therefore searched for evidence of a fracturing or disruption in life narrative. Absence of an identified fracture (in other words continuity of narrative) was identified as Biographical Flow. As cases of Biographical Flow and Disruption were identified, they were compared to ensure that each described something similar. A deviant case was identified, falling outside of the descriptions of the two emerging categories. This was categorised separately (see section 6.5, p108).

The holistic-content analysis involved further detailed reading and re-reading of the transcripts allowing me to re-familiarise myself with the data. Open coding of all transcripts (supported by NVIVO software version 1.3) identified emerging themes in light of the research question, stated aims and theoretical perspectives. Themes were sought which described and/or explained illness experiences, emotional experiences, and the impact of narrative experiences on the individual. As new themes were identified, including in newly collected interview data, existing transcripts were revisited to explore the data in light of the newly forming ideas. Comparison of themes between the individuals within each biographical category sought to move the analysis from a descriptive account of personal experience to an identification of shared themes or processes which might account for similarities and differences in experiences. Results were exported into an Excel spreadsheet to facilitate this cross-case analysis.

This iterative process of re-reading and coding (described further in appendix A7) led to identification of axial codes, namely broad themes which appeared to explain or tie together a group of previously identified open codes. Cross-case comparison between biographical categories (analysis of divergent categories) was used to further develop the interpretation, both to deepen understanding of the emerging concepts and start to identify and explain commonalities and differences. Eventually I identified themes which were unchanging despite further iterations. At this point, each interview transcript was re-coded to identify the totality of that theme for each individual. For each participant, a coding framework was produced which included all the data contained within each interview which fell under the heading of a particular coded theme. These individual frameworks formed the basis of the analytical descriptions in the subsequent chapters.

The interpretive process was guided by the Hermeneutic Canons of Interpretation described by Radnitsky (1968) as adapted by Kvale (1996: 48-50): see Box 5.2. The processes of sampling, data collection and analysis continued until I reached a point of coherence (Kvale 1996). This describes a point where the emerging analysis was adequate to explain the range of experiences described in the data: both at an individual level and at the level of the complete data set.

Box 5.2: Hermeneutic Canons of Interpretation

(adapted by Kvale 1996 from Radnitsky 1968)

1. Moving back and forth between the parts and the whole
2. Meaning is found when you have found "good gestalt" or coherence
3. Testing of part interpretations against the global meaning of the text
4. Autonomy of the text - can be understood in its own frame of reference
5. Knowledge about the theme of a text
6. Interpretation is not presupposition-less
7. Every interpretation involves innovation and creativity

The iterative nature of the process is described further in appendix A7. Interim models and thematic schemes were identified as 'not yet right' by their inability to adequately explain all the data. I often reached a point where my emerging ideas could explain part of the data, but left me trying to 'cram' other ideas in – like a square peg in a round hole. After 17 interviews, I had identified an account which appeared to explain the data as per the boundaries of the theory and my research question. The subsequent two interviews provided no new insights or dissent. Only at this stage did I feel I had reached a point of coherence (Kvale 1996). I recognise and acknowledge that other interpretations are possible. Coherence represents an explanation within the set of assumptions outlined in this chapter. It does not purport to offer 'truth' since this is not part of the subtle realist framework of this thesis.

I was responsible for the primary analysis as required by the PhD process. However emerging findings were discussed with my supervisors (Professors Lloyd-Williams and Dowrick) and my external advisor for the qualitative study (Professor Payne) who commented on consistency and confirmability. The process included collectively reviewing transcripts in the initial stages of the analysis. Having coded transcripts independently, we met to discuss agreement and non-agreement: both in terms of which parts of interviews we felt were important, and in our interpretation of them. Subsequently, we met to discuss the emerging analysis, including its consistency with the primary data set, and its resonance (or otherwise) with existing theoretical ideas. These discussions supported the processes described in Radnitsky's Hermeneutic Canons of Interpretation (Box 5.2, page 89); and supported a collective agreement of when the emerging analysis had reached a point of 'coherence' (Kvale 1996).

5.9 Presentation of the account

The results of my analysis are presented in the subsequent three chapters. The presented analysis is supported by quotes from the original data, which were primarily selected to illustrate the emerging themes. The majority of quotes are representative of general themes found in most interviews; however some are clearly identified in the accompanying text as representing outliers. I have attempted to select data from a range of respondents in order to provide evidence that my interpretation is supported by the full data set, and not based on an analysis of only a selection of the respondents. Although the quotes are intended to illustrate the analysis and therefore aid the reader in identifying the themes arising, I recognise that others may identify alternative explanations for the data contained within them. This highlights the limitations of using quotes to illustrate a complex qualitative analysis. Each quote is a small part of a larger dataset and has been interpreted within the context of the whole dataset for that individual, the collective data from all the interviews, and my stated theoretical perspectives (subtle realism, phenomenography, and an interest in Biographical Disruption and Flow). Taken in isolation, a number of alternative interpretations may be possible.

In order to understand the quotes presented, the reader needs to know the transcription devices used within this data set. All additions made to the narrative text during the transcription process are indicated by placing them in square brackets, [ ]. Examples included pauses, where significant to indicate mood, which were identified in [ ] with approximate timings, and in non-italicised font. For example in the case of Mark, the lengthy pause shown in the following excerpt revealed the extent of his upset at the thought of the effect of his illness on his family.

> Mark: "*You do get depressed. I got depressed. But it also affected my family – my 2 kids and my wife.* [pause 5 secs]. *What was I saying. I did go – I went to a therapist. I don't know if you know – I don't know how much information [the practice] have given you* JR*: That you've got lung cancer.* Mark [interrupts]: *Right. I had an operation to cut it out – two lots of chemo, one lot of radiotherapy. So pretty much two and a half years. It was a rough two and a half years. So as I say, from what I've been through [...] my wife [...].*"

This quote also reveals a number of other transcription points. All identifying features were removed from the text and replaced with a non-identifying descriptor, again placed within square brackets to indicate a deviation from the primary narrative. For example, "*[the practice]*" in the quote from Mark cited above replaces the identifiable descriptor used by Mark. Words which directly replace speech in this way were written in italics. This contrasts with the non-italicised statement in the same quote, "[interrupts]". The square brackets indicate that this is an addition to the text. The use of non-italicised font indicates that the insertion is a field-note or explanatory note. Where periods of speech were too unclear to transcribe, they were marked as 3 dots within square brackets [...].

Field notes were embedded into the text when transcribing but clearly identified as not part of the interview narrative through the use of square brackets and non-italicised font. For example, whilst listening to the tape of my interview with Angela, I could hear a vacuum-cleaner in the background which prompted me to remember her husband's behaviour at the time of the interview. I had not recorded his actions in my field-notes and so included a record in the transcription notes.

> *Angela: "So he just rearranged everything to fit me in. I went in on the Sunday and had the operation on the Tuesday."*
> [Note to Jo – husband is in and out of the room adjusting television settings, now vacuuming, and is clearly uncomfortable with the whole process]
> *Angela: "But he was so lovely."*

Emphasis was shown by <u>underlining</u>. The quote below from Mary also shows a further example of a reflective note made whilst transcribing. It reveals my concern that Mary's tone of voice in the recording did not match the sense of the written words on the page.

> *Mary: "But I'm getting really, <u>really</u> tight feelings all round the ribs you see. I don't know whether I'm right or wrong Joanne, but I think it might have jumped to the other side now. Because I've been getting like a jagged pain on this side. But overall, I'm doing really, really well. I'm not lying down to it or anything at all."*
> [voice still quite flat. Not something I particularly picked up at the time. But does she protest too much? She was very eager to be involved. Is there a need here that isn't being met? Is she 'depressed'?]
> *Mary: "I think, you know, if I can overcome it for a certain length of time and live a decent type of life for the next couple of years like, I'll be lucky."*

As described on page 88, the totality of data for each coded theme was identified from each interview transcript. Quotes in this thesis may therefore include data from two or more different places within the interview. Non-continuous text is identified using three dots ... as shown in the quote below from Jenny. She had been talking about her altered priorities since her diagnosis, and returned to the same theme later in the interview. Both areas of text were coded under the same theme of *altered priorities*. The three dots ... indicate that the text was not a continuous spoken phrase in the interview.

> Jenny: *"You take it for granted. Flowers and everything and the birds...You think more deeper some how."*

5.10 Presentation of the account: establishing trustworthiness

5.10.1 *The criteria for establishing trustworthiness*

Having described the process by which I sought to identify a coherent analytical account of my data, I turn to consider the question of trustworthiness (Lincoln & Guba 1985), or why anyone should believe my analysis (Bosk 1979). The study adopted a subtle realist stance arguing that truth was not an appropriate quality marker by which to judge knowledge. However I have also rejected a relativist approach where all knowledge is deemed to be equal. I therefore turned to the work of Doucet & Mauthner (2002), who argued that knowledge should be judged by reviewing the processes and assumptions which underpin its production. To do this, I used the criteria identified by Maxwell (2002) suitable for subtle realist research. I begin by describing each in more detail before outlining the processes I will use to assess my research against these standards.

The first of the five criteria is descriptive validity. This refers to the requirement for an accurate recording of what happened or was observed by the researcher, and forms the basis on which other criteria build. In the case of interview based research, tape-recording of an interview can be used to demonstrate that a participant did make a given statement. Field-notes introduce greater uncertainty. Although they are important for contextualising the transcribed narrative (for example Angela's husband's vacuuming described previously), they rely on the researcher's interpretation of what was happening and what is important to record (for example my assumption that this activity was indicative of unsettlement rather than simply a routine activity). Two observers of the same event may therefore produce different recorded observations (or data) about that event. Maxwell (2002) emphasised the need for rich and transparent descriptions of all the observations used in analysis.

The second criterion is interpretive validity and refers to the processes used to interpret observations and identify meaning (ibid). Both Maxwell (2002) and Lincoln & Guba (1985) describe interpretive validity as an assessment of how accurately the interpretation reflects the individuals' perspectives, including an emphasis on the neutrality of the researcher. However as with description, interpretation is dependent on perspective, as described in the Hermeneutic Canons on page 88 (Kvale 1996).

The third criterion is theoretical validity, which looks at the research outcomes: the presented account (theoretical ideas) from the research, rather than the processes. Theoretical validity questions how well a research account moves from a description of the participants experiences to an interpretation; and thus how well the account serves as an interpretation and explanation of the phenomenon (Maxwell 2002).

Maxwell (ibid) acknowledged that these three features are interlinked and often hard to distinguish. All refer to how well the research account applies to the situation studied. The final two criteria refer to the application of the findings, and the 'validity' of the knowledge generated beyond the boundaries of an individual study. The first, generalisability, questions the ability to infer from the account. The question of whether qualitative research findings can be applied to other situations or populations is a common cause of concern for those who wish to use research findings to inform practice and policy (Murphy et al 1998). Whereas quantitative research relies on statistical theory to support generalisation, qualitative research relies on what Kvale (1996: 233) calls "analytical generalisability". Research generates theory; it is assumed that a well developed theory may offer insights into other situations or processes.

The second criterion in this group is Maxwell's (2002) notion of evaluative validity: the utility of the knowledge produced and its 'so what' factor are markers of 'good' research. This is a difficult and contested area. The question of utility opens up a whole set of questions on the nature and purpose of research and the generation of knowledge (Dant 1991, Murphy et al 1998). How does society decide what knowledge is of use or value? However within health services research, utility is a key marker of quality (Boaz et al. 2002, Solesbury 2001). My research question also specifically demands that the output be of use to a practising GP.

5.10.2 *Measurement against the trustworthiness criteria*

Based on Maxwell's (2002) descriptions and the broader literature, notably Lincoln & Guba's (1985) detailed account of processes for establishing trustworthiness, I identified the mechanisms by which I would assess the trustworthiness of my analysis (See Table 5.3). A detailed account of the application of these criteria to my analysis is given in Chapter 9. I have deliberately omitted two quality markers commonly mentioned in the literature, namely member checking and triangulation (Lincoln & Guba 1985, Murphy et al. 1998). I will therefore briefly explain why they were not used in this study.

Lincoln & Guba (1985) emphasise the importance of member checking or validation, since they argue that the credibility of research relies on the research account being credible to the research participants. This reflects their theoretical perspective (naturalistic inquiry), which argues reality is that which is constructed by people living their lives. Individual participants therefore act as the reference point to establish truth. Whilst I support the concept of authenticity when considering the 'truth' of an individual narrative, my interpretation of the collective dataset is influenced by other considerations including the theoretical position of my study. To take the results back to participants would invite potentially interesting and informative reflections on this wider interpretation. However I would argue this would constitute new data and an extension of the research rather than a validation. In this study, I therefore rejected member validation as a measure of validity but accept it may be a useful step in future development of the research.

Triangulation is a further tool suggested for establishing credibility including interpretive validity. It involves seeing a phenomenon from a number of perspectives simultaneously to gain greater insight into the phenomenon. There has been no attempt to triangulate within the qualitative arm of the study e.g. through use of multiple data sources or investigators (Murphy et al. 1998). However the totality of my thesis represents theoretical triangulation. Some have argued that triangulation adds validity to the emerging ideas, others have suggested it adds depth and breadth rather than inevitably validity (Barbour 2001). I will return to this point in Chapter 9 when I look at the thesis as a whole.

5.11 Summary

Having outlined my approach to data collection and analysis, in the next three chapters, I will describe the results of my analysis.

Table 5.3: Criteria for establishing trustworthiness

(adapted from Lincoln & Guba 1985, Maxwell 2002)

Criterion	**How I will demonstrate it**
Descriptive validity	Transparent and honest account of the process including: data available for review, dense description of research methods, stepwise replication, peer examination, prolonged/varied time in field, reflexivity, and peer examination.
Interpretive validity	Transparent and open account of process including: interpretation supported by evidence from data, reflexivity, peer examination, negative case analysis, meeting requirements of Radnitsky's Hermeneutic canons (as cited in Kvale 1996)
Theoretical validity	Through production of an account which is grounded in existing theory, describing an iterative process demonstrating structural coherence and "referential adequacy" (Lincoln & Guba 1985: 313)
Generalisability	Through use of theoretical sample, clearly described, also dependent on establishing theoretical validity
Evaluative validity	Through a reflexive account of the context of research and identification of the 'so what'.

Chapter Six: Results – Biographical accounts

6.1 Introduction

In this and the subsequent two chapters, I present the results from my analysis of interviews with 19 people with advanced metastatic cancer. My aim was to explore whether the impact of illness on an individual's life narrative may offer insights into emotional health experiences. I begin in this chapter by outlining the three categories of biographical effects identified from a holistic-form analysis of the interview narratives. For each category, I emphasise the associated emotional health experiences.

6.2 Biographical effects

People's life stories were described and revealed throughout the course of each interview-narrative. Most interviews started with an illness-narrative: an account of an individual's life from around the time of diagnosis. Other times in people's lives were also described or revealed elsewhere in the interviews. It was therefore possible to construct a biographical account, albeit one which was neither complete nor comprehensive. My analysis did not focus on how individuals constructed their account: which aspects of their lives they chose to reveal, with an interpretation of what insights into themselves that offered. Instead, as described in Chapter 5, I used a holistic-form approach as described by Lieblich et al. (1998) to look for significant structural points in the revealed 'plot'. In particular, I looked for evidence of disruption: a profound disturbance to a continuity of life narrative. As a result, I identified three categories: Biographical Flow, Disruption and Shift. I will describe each in turn before discussing the overall implications of the identified results.

6.3 Biographical Flow

Of the three identified biographical categories, a continuity of life narrative - so-called Biographical Flow - was the norm. This group was identified by the absence of any profound disruption in people's life-narratives. Participants revealed that life events, including experiences of disease effects and treatment regimes, were incorporated into their ongoing lived experiences. They described periods of 'turbulent flow', transient episodes where life was difficult. However, there was no sense of a profound upset: where life had come to a halt (as seen in the Biographical Disruption group). To illustrate these ideas, I present four case studies before discussing the overall implications.

6.3.1 *The case of Albert*

One of my earliest interviews was with Albert, an 84 year old man with lung cancer. I interviewed him at home, where he lived with his wife. He was a war veteran with significant problems related to arthritis and shrapnel injuries. He attended a day centre once a week, and had done so since before his cancer diagnosis. The cancer had really had little additional impact on his life.

So much so that in the first stages of the interview, I was worried that Albert was not aware of the severity of his diagnosis (and was therefore concerned about the potential effects of questions I might ask him). He talked openly about the shock of the diagnosis with cancer, but his subsequent account of how much better he was feeling didn't reveal a concern about prognosis.

> Albert: *"[The diagnosis] didn't catch me unawares if you know what I mean...[But] as I say, it took me aback...I had a like a nark at the back of my throat, and now and again it was smarting and I couldn't work out what it was. And in the very early hours of the morning, if I lie flat on my back, I'm fighting for my breath...Anyway I was bringing this fluid up and it was full of blood. Thick blood you see...So they took me [to the hospital]. And on the left side, they said 'you're all clear'. 'That's the best part of my body' I said, 'This is my damaged part'* [pointing to the right]. *So they put the camera down there, and it was full. That's when they found it. So as I said, in a way, it wasn't a surprise...I lost my grandchild a few years ago with leukaemia so I know it's in the family somewhere...[But] I'm not discharging blood in the phlegm [any more]. It's just like a thick substance. So I'm hoping they've caught it in the early stages."*

He went on to talk about the treatment he had received, and revealed his current health status as good. The second half of his interview offered an account of his time spent on normal everyday things: spending time with his wife, or at the day centre (a facility for older people rather than a specialist palliative care centre).

> Albert: "*I do a bit of gardening and that...[My wife's] been out [this morning] at the hairdresser's, and I go in the back kitchen and do the dishes as best I can. Prepare the vegetables. But I can't do any cooking. And as I say, the full day that I go [to the day centre], the ambulance comes and picks me up at 9 o'clock til 5 o'clock everyday. So I'm out everyday and there's somebody supervising me you see.* JR*: What do you do at the day centre?* Albert: *Well, I walk around* [wife interjects*: 'Play bingo. He's been thrown out because he keeps winning!'*]*...I'm mixing with people. And I talk to the regulars.*"

The threat from his illness did not unduly concern him, so long as he was able to continue to go to the day centre and live his life. He did reveal evidence of some transient upset: his frustrations with his physical limitations and his concerns about his wife, and the lack of support she got from her children.

> Albert: *"No I am very impatient, I'll give you that* JR*: Have you always been a bit impatient or has that changed?* Albert*: No it's changed over the years. I used to be all right at one time. But in general, I think. Like I said, we can't go out together because of me being in this situation. Because of this, I've got a convene on at the moment and I've got to have someone to keep emptying the bag...What I'm concerned about, I can see she's* [referring to his wife sat next to him] *deteriorated in health. I can see it in her... You see I've made an application now to see if I can get her to come to the day centre. Spend a couple of days. Cos you see all the children – they're all working. They're living away and they're all working. And the eldest child said 'Do you know what's wrong with Mam?'. And I said 'Yes I know what's wrong with her'. So I said 'She wants company'. I said 'You live the nearest. Why don't you come? Even if it's only at the weekend? And take her out for an hour?'*

However overall, his actions and narrative describe biographical continuity with no evidence of a profound emotional upset.

His wife was present throughout the interview and this may have influenced the narrative he told, including his apparent lack of concern about his prognosis.

However a similar sense of continuity associated with a complication arising from a shrapnel injury he sustained during the war suggested continuity was actually part of his way of living life.

> Albert: *"But [the doctor] turned round to me and he said, 'There's only one thing about it, you'll never be able to walk again'. So I said, 'Oh why's that?' He said 'Because you're injured'. I said, 'Well listen I don't believe in that.' I said, 'I want to try and walk'...Every time the ward doctor comes round, every morning he bypassed me. He wouldn't even look at me... So I said, 'Well I want to be able to walk'. So I asked the physio. She said, 'Yes – what I want you to do is just walk round the bed'. I said, 'I'm not satisfied with that'. Anyway, I walked the full length of the ward and she ran after me!"*

6.3.2 *The case of Ron*

Similarly Ron, a 67 year old man with Chronic Lymphocytic Leukaemia, offered an account of continuity associated with emotional stability, again fitting within the category of Biographical Flow. Although he had to deal with physical health problems, he was still able to 'get on with life'.

> Ron: *"I have to go to hospital every three weeks for some - I don't know what it is. I have eight bottles of this stuff* [chemotherapy]*...But as far as I can see, it is counteracting the thingy* [cancer] *you know. Because I'm not as bad... At the present time I've got a chest infection. I've had vaccinations to try to prevent it, but they haven't worked... But I've been to the doctors because me and the missus are going away next week...I need to be as fit as possible. Because my wife's in a wheelchair you know...We're in a club - a pensioners and disabled club. And the fella that runs it has got us a free holiday...The aspects of my life as far as I am concerned...are for me to be able to get up of a morning time. Right? Go to the shops. Get [my wife's] breakfast and get her up out of bed...And to make sure that she goes out - otherwise if she doesn't go out, she gets a cob on!...We've been married 44 years...We back each other up, we help each other out. That's the only way we do it - we work together. And we were told when we first got married that it wouldn't last a year. Well the people who told us are dead – no longer with us...It worried me when I first found out what was wrong. But I think after a time, you take it in. You just accept it. Cos there's nothing you can do about it. And I've coped*

> *with it up to now alright...The most important thing to me as far as I am concerned...is to attend the hospital regular and also go and get the treatment at the hospital."*

The cancer treatment had been incorporated into his everyday life; continuity was maintained, and the primary focus in his life was still his relationship with his wife. He also described transient irritations: associated with family concerns and his physical health. However, overall the pattern was one of Biographical Flow associated with wellbeing.

6.3.3 *The case of Linda*

Linda was a 54 year old nurse: a wife and mother, who had recurrent breast cancer and was receiving only palliative treatment. She described feeling well at the moment as she was in her "*good week*" of her chemotherapy cycle. However the broader account was also one of doing well.

> Linda: *"Through all of this, [waiting for the diagnosis] was the worst time. But I suppose it is for everybody, having tests and you know waiting and waiting for results you know. It's the not knowing isn't it?...I've got two more treatments. I have my fifth one next Wednesday and the sixth I think is the 1st of December. Which is rather nice because I've worked it all out - I'll be ok for Christmas! I said to my husband, 'I won't be able to do Christmas quite the same, but I'll be ok for Christmas!'...I've started planning for Christmas and sorting out the recipes. Cos I love cooking. And that's the one thing I find really, really difficult. When I'm feeling grim. I don't enjoy cooking because the smells...And I feel so positive. I know there aren't any guarantees in this life but I sort of feel well, I'm going to be different. Because I've got too much to do. And you can't just sit down and mope about it – you've got to get on... I mean apart from the side effects of the chemo, which I know, I don't feel like a sick woman, and I certainly don't feel like a dying woman...I am a bit of a forward looker. I think when you've got children, I think you have to be because you're always concerned for their future...I do like to plan ahead and I do like to know what's coming and making plans... I mean I'd like to have a holiday next year but I don't think we'll get one because I don't think the finances are there at all. But yes, I look ahead to my children, to what*

> *they're going to do. That doesn't mean I'm living my life through them. But looking forward to what they're going to be doing."*

Other people (including Joyce, Jenny and Pat) described a similar pattern of a transient period of upset at the time of diagnosis, but with an overall sense of wellbeing through continuing to live with their families.

6.3.4 *The case of Nora*

Nora was a 63 year old woman with lung cancer who lived alone, albeit with family close by. She spoke of being a single mother and of a life spent struggling along with whatever was thrown at her. Her narrative revealed a task-focused biography: one which centred on getting things done, rather than maintaining a continuity of a narrative account of herself. Thus she described:

> Nora: *"My family are the <u>most</u> important thing to me. And being able to live from one week to the next. I mean I've always had that with bringing the children up and I think that's why I've been so independent because you know I worked. I used to sew. I sewn an awful lot, you know, to earn extra money so that the children wouldn't go without. Specially for Christmas and birthdays and all that. Cos I thought – there's no way they're going to do – you know, have less than other kids. But I used to sew my fingers to the bone. But, you know, it did get done."*

In the middle of her interview, she received a telephone call to say that a friend she had met at the oncology unit had just died. She was clearly upset by the news, but asked to continue the interview: a further example of her task focused approach to life. She remarked:

> Nora: *[My daughter] was so lovely with [my friend who has just died] as well. [My friend] said, 'Your daughter is <u>lovely</u>'. [My daughter]'ll go mad [about the news]. But maybe she* [her friend] *is better off. You know. Never mind. So, go on with the rest of the interview now. Go on."*

Her illness narrative was one of continuity with no major periods of upset, emotional or otherwise. She spoke of times in her illness which had been more difficult than others: losing her hair, the tiredness of the chemotherapy and now radiotherapy. Her mood dropped when her physical health was worse, partly through concern that the treatment may not be working. However keeping going was part of her way of coping with her illness, including with her periods of lower mood or anxiety: again, a task oriented approach.

> Nora: *"I'll keep myself busy. I'll do something. I'll, you know, tidy round or you know get the polish. Sort of thing like that. To take my mind off things. I just say to myself you know 'Shake yourself'. Umm shake yourself up. You've got to haven't you? No one else'll do it – only yourself. So you know that's the only way I cope with it really...Sometimes it seems a long trek and I think this is never going to get any better. And then I'll have a couple of good days and I'll think – yeah I'm bucking up. And then I'll hit the bottom again and that – you know – puts the low ebb on it again. But they've said I'll have up and downs like that all the time you know... [But I only] have say a down day....And if I wake up and I feel, 'Oh good, I can cope today'. But then another day I'll think, 'No I just want to stay in bed'. But you don't really know until you get up. It's queer...[But] I've coped a lot on me own cos I've brought me children up on my own so I've had to be like the base and take the initiative for everything. I think that's what makes me so independent and you know makes me do things. So maybe that's the way I am. I just deal with it myself as far as I can. I'm not saying I don't have a little cry now and then. You know. But then I'll wash my face and I'll think, you know, buck yourself. You know. Don't be stupid. And I'll tell myself off. And, you know, you carry on again."*

6.4 Biographical Disruption

By contrast, two people described a period of profound upset in their life-story associated with being unable to continue with their lives. In both cases, continuity had been restored by the time of interview. Both described a significant emotional disturbance at the time of the fracturing of their life narrative.

6.4.1 *The case of Mark*

Mark was a 45 year old man with metastatic lung cancer. His account revealed three phases in his life-story. Firstly there was a period of continuity: living his life as a father and husband and even dealing with his primary diagnosis of lung cancer. Then came a profound disruption at the time of his terminal diagnosis, associated with severe emotional distress. However he concluded with a third phase of restored continuity: of Biographical Reconstruction (Williams 1984).

Phase 1: Continuity

> Mark: *"Before I got my lung out, I was a very energetic person. I used to go cycling with my kids. I used to go kayaking with my kids. I used to [...] with my kids, we used to go walking. We'd think nothing of cycling – you know – twenty mile a day something like that. We walked the whole length of X beach... First time I discovered it was cancer and got my lung out. It was ok – I didn't know what to expect. I was more – not scared. Urm anticipating, worried. Not worried, particularly worried. I didn't know what I was going to go through so I didn't have any idea.... I come home, just finished work. Cycled home. Blowing a gale. Somebody walked out in front of me. Came off the bike. My ribs hurt a bit. Had a couple of beers, went to bed, woke up and screaming pain. Goes to doctor, doctor gets ambulance, I get xrayed...Never thought too much about it. Doctor calls me in and says there's a shadow on your lung...[Later in the hospital] the doctor says to me, 'You have got cancer. I'm going to remove a third of your lung'...Now on the day, they took me whole lung out. His words, cos I used to smoke, his words were, 'You've got one good lung. Look after it. It was so badly diseased, I had to take the whole lot out'. So I packed up smoking. Just like that."*

Phase 2: Disruption

> Mark: *"I didn't get depressed [the] first [time], but I think it was the second lot that sort of like hits you. What was bothering me was 'Oh I've got to go through this again'. The chemo – that makes you really, really ill it does... Cos I knew what to expect – when they found it the second time. You know it's erm – very demoralising... Then I got that infection half way through the last lot of chemo and that really. I couldn't eat, I couldn't talk about it you know.*

> *I mean I was cooking food but I wasn't hungry. I was hungry but couldn't eat it. All these things. I mean it sounds silly – it sounds daft to people. But I mean you know. You've got no energy. You just want to sit there. With the infection – I didn't know it was an infection. I come a week later to see the doctor and he said, 'Oh you've got an infection'... Then after that, yeah. That's when it really came but it did build up slowly. And that's it bummmph... You feel* <u>*black*</u>*. You feel 'why me'? And you can't do things. I was* <u>*angry*</u>*, very angry – extremely angry. I mean you ask my kids. They're the people to say, not me. See my wife and kids and ask them what I was like going through. I imagine part of it might have been the medication as well – the steroids. And so that's probably part – but it does make you angry. You shout at everybody...I mean it was dark days for a while you know. My wife says I was suicidal [...] like taking all my pills. She was scared. She actually hid them. But yes, you do feel urm – rejected as well I suppose. I don't know, I find people, if you say you've got cancer, it's like AIDS or TB. And it's like ooww...I mean you can sit back and talk in reflection and think how bloody daft that was. But at the time it wasn't. At the time it was really sick of it – I thought I'm going to chuck myself under a bus here. I felt like I'll just have no treatment at all and just get on with it."*

<u>Phase 3: Restored continuity</u>

> Mark: *"I think I'm on the road to the mend. I don't know. I mean I'm happy as Larry now. I still have my down days. I still get down. I've just been back to the hospital and they've said they're going to radiate my neck again. They're going to do that for six weeks. So I think there's something there. But I'm not sure what it is. I think they err on the side of caution...But as I say certainly since I've had my chemo and before Christmas – got it out of my system. I'm feeling great...I'm a [volunteer at a local centre]. I do that a couple of days a week. And generally just be a house husband....I might not be sitting here today if it had all gone different. You know what I mean. If this hadn't cured the first lot, I might not be sitting here. And I think now, well heh hey so it's a house! Why do you need to be rushing? I don't run for buses any more! You know – if I miss a bus. Well ok, there'll be another in a few*

> *minutes. As long as the lads have got clothes on their back. Meals in the house. That's it."*

Mark described the importance of being told he had depression in helping him move from phase 2 to phase 3. Thus for him, diagnosis was an important part of reinstating Biographical Flow – a process which was similar to the Biographical Reconstruction described by Williams (1984).

> Mark: *"The counsellor turned round and said, 'You've been referred to me because apparently you've been depressed.'* JR: *Did you agree? Did you think you were depressed?* Mark: *Yes. I thought. I knew I wasn't right. I thought it's not right this – you know what I mean? You know, I was talking to [my GP] and he told me about the counsellor. And I thought – yeah, I see where you're coming from. That's what I have. I don't think that you see that it's depression. You know what I mean. That feeling – well. Feel that people don't care and. You know. That you're on the edge. It was lucky that I went to the doctors when I did."*

6.4.2 *The case of Joan*

Joan was a 55 year old woman with metastatic breast cancer. She described a very similar sequence of life events to Mark. Her primary diagnosis of breast cancer was a shock, but she had dealt with it. However following her diagnosis of recurrence, she was told she had spinal metastases which were pressing on her spinal cord. She therefore had to start a course of radiotherapy which left her feeling physically drained. Her sister then died unexpectedly. The culmination of physical, mental and emotional exhaustion led her to a point of breakdown.

> Joan: *"And I come home to find me sister dead in bed and. It was awful. Such a shock...I think it was going in the hospital, thinking that I had compression of the spinal cord. And then coming out and getting told well you've got to have the radium on your back. And I had really bad effects after the radium...and I couldn't eat, couldn't drink... And I was in constant pain for six weeks and I had no energy. No one prepared me for how bad it was going to be...I felt so ill and I didn't know what was the matter with me. And I was panicking and fighting this tiredness and this. .. And I ended up in floods of tears."*

At this point, she was taken by a friend to see her doctor, who diagnosed her as having depression. Her life-narrative from this point showed a rapid improvement. As with Mark, restoration of biography appeared to be associated with being diagnosed with depression. The existing theory on the pharmacological action of antidepressants cannot explain the changes described in the following quote. Instead, it suggests that the diagnosis provided a meaning for her experiences and therefore a route to Biographical recovery or Reconstruction (Williams 1984).

> Joan: *"So she said to me, 'You're giving me all the classic signs of depression, you know?' she said...So she got me [antidepressants]... And then I took them - second day and I thought, I'm starting to feel a little but more energetic. Like I've got a bit more energy. And by the third day, I as feeling a lot better and I thought, 'It must have been the depression'. Because I'd gone through so much."*

In both cases, Biographical Disruption appeared to be precipitated by a period of profound physical and emotional exhaustion. It was associated with emotional distress, which in both cases was severe enough to be diagnosed as indicative of 'depression'. Diagnosis in turn contributed to a resolution of the disturbance and a restoration of continuity.

6.5 Biographical Shift

The final category of Biographical Shift has not been described in the existing literature. In one interview in the sample, there was no evidence of the profound disruption identified in the category of Biographical Disruption, yet there was a marked change which had not been apparent in other people in the Biographical Flow category. Angela was a 45 year old woman who was diagnosed with terminal ovarian cancer just five years after her sister had died of the same illness. She was a wife and mother of a 16 year old daughter, and had worked all her life at the Benefits Agency. Analysis revealed a continuity in her life narrative but with evidence of a 'shift' in the nature of her account; in her case, precipitated by the cancer diagnosis.

Her account of life before her diagnosis reveals an account of a woman who was ground down by day to day events.

> Angela: *"I've worked all my working life. I actually worked in a sweet shop believe it or not for weekends when I was younger. I started working in the Benefits Agency when I was 17 and I worked there until this happened. So I've always worked...[The Benefits Agency] changed a lot in the last ten years and I didn't really enjoy my work anymore. It was a lot of pressure – because I was the oldest, a lot was expected of me and a lot extra was put on me. I went part-time and they still gave me full-time work and expected me to do a lot more... And everything was just piled on top of you. So you come home absolutely exhausted and feeling as if you've got nowhere. And I used to hate going in."*

She also spoke of juggling things at home: in the running of the family home, with the pressures of work and school commitments for her husband and daughter as well as herself. She described herself as a "*logical*" person, which was necessary to for her to accomplish what needed doing. Whilst she met the demands placed on her, this came at a cost of exhaustion.

When she was diagnosed with terminal cancer, although she described it as a shock, she also revealed a sudden shift in her narrative.

> Angela: "*Well I'm going to admit here that I am – or should I say I <u>was</u> – very naive about the NHS. I was quite a healthy person...They found a small hernia. Which was actually the disease coming out...When I had to go back to the clinic to find out the results of the small hernia, that's when I really found out more about the NHS. I actually saw the consultant. And I'd never seen him before and he was lovely...And he had this plain clothed lady with him. And I thought, 'Who's she?' And he introduced her as* [name]. *And I thought, I still don't know who she is but I'm not going to ask – I'm not going to look stupid! And he did examinations and. And I said, 'Can I just hold someone's hand.?' And* [name] *straight away [gave me her hand]. And it turned out she was one of these specialist nurses. Which I didn't know existed. She was lovely. Not what I would have expected. He'd done the examination and he thought it might possibly have been in the bowel. So he said, 'I'll refer you to a bowel specialist'. I said, 'Ok', and what I expected was a letter in a few weeks saying whatever. And with that, he just strides out the door and goes to*

> *the clinic across the way and says, 'I've got a patient here. Blah blah blah. Would you see her now?' So I was dumbstruck!...They took me across and I saw this consultant and I was absolutely amazed. And I thought – the NHS doesn't do things like this!...And he said, 'We'll sort it for you. And I'll arrange a scan.' Now this was on the Monday that I actually saw these two consultants. And as I say that week was sheer hell. [The specialist nurse] phoned me every day to see how I was and she offered a great deal of support. I could phone her anytime. I had her direct line and I had her bleep number. Now that's just something I wouldn't have expected... And believe it or not I got the scan on the Friday. I had the scan on the Friday and she phoned me on the Monday and she said. 'We know where it is.' And that was like a week to the day that I'd been diagnosed. And I was so impressed. It was unbelievable. And I went in again – and saw the consultant again. And he sat and explained where it was, explained what he thought would probably happen and said, 'Obviously I'm not a gynaecology consultant so I'll refer you to one.' So again I expected, you know, a letter in a couple of weeks. Next thing you know he pulls this book out and disappears out...He was on the phone to the consultant. The consultant was actually going to London that week but he said, 'No ask her to come to my clinic on Wednesday.' This was on the Monday. He said, 'She'll be seen by one of my Registrars and book in so to speak. Do all the pre-op and everything.'...They have like meetings of a morning where all the current and new cases are – and they discuss priority and whatever. And to cut a long story short I got a phone call on Friday, could I come in on the Sunday. Well. Again I was a bit gobsmacked so to speak".*

There was a qualitative shift in her biographical account: from one of weariness and burn out to one of being valued and supported. She described:

> Angela: *"It's like a different way of life!...I'm still doing what I was doing before. I'm just enjoying it more...Now I do what I want, when I want...The priority is me now. Selfish I know... And something I've always wanted to do but never had the chance to do because I've always worked, is do crafts...So I sit and do these craft cards. And I actually sell them. And I get a great deal of satisfaction out of doing that."*

Unlike the accounts in the Biographical Disruption group, there was never a fracture in her life narrative. Instead her diagnosis and subsequent care was associated with continuity but with a shift in her account which was also associated with emotional wellbeing. There is overlap here with the work on stress-related growth described by Siegel et al. (2005), which proposes that self-esteem and/or relationships with others may be improved by dealing with an adverse life event. Their study of women living with HIV/AIDS found that many were 'better off' having lived with their illness experience, and underlined the importance of social resources including relationships in supporting that personal growth. In Angela's case, the relationship with her medical team was significant in starting a process which moved her from feeling down-trodden to being of importance.

6.6 Discussion

I have described three distinct biographical patterns within the interview data: Flow, Disruption and Shift. Biographical Flow was the norm and described a continuity of life narrative, albeit associated with transient emotional disturbance tempered by good days. Biographical Disruption was associated with a profound emotional disturbance, diagnosed in both cases as depression; subsequent Biographical Reconstruction was associated with improved emotional status. Finally Biographical Shift was a profound shift in life narrative from oppression to relief, associated with an improved emotional status. Thus effects of illness on biography appear to offer a prediction of emotional effects.

The process of Biographical Shift did appear to lead to an improvement in emotional status. However in the other two biographical categories, the causal path was less clear. It was difficult to say from these retrospective accounts which came first: the emotional state or the biographical pattern. Giddens' (1991) theoretical work on self-identity predicts that fracturing of a life-narrative would cause an emotional disturbance. However there is a suggestion within my data that emotional disturbance or exhaustion was a causal factor in the Biographical Disruption experienced by both Mark and Joan.

The analysis was limited in terms of its ability to explain why peoples' experiences differed. Table 6.1 compares the characteristics of the participants in each of the

Table 6.1: Showing participant characteristics by Biographical category

	Reference	Age (yrs)	Sex	Tumour	EDS score	Lives alone	Attends hospice
BIOGRAPHICAL FLOW	Albert	84	M	Lung	6	N	N
	Ron	67	M	CLL	10	N	N
	Helen	66	F	Colon	16	Y	N
	Nora	63	F	Lung	16	Y	N
	Marjorie	61	F	Melanoma	20	N	Y
	Jenny	71	F	Lung	17	N	Y
	Mary	63	F	Lung	18	Y	N
	Linda	54	F	Breast	17	N	N
	Peter	62	M	Prostate	12	Y	N
	Jim	83	M	Oesoph.	12	Y	N
	Pat	64	F	Lung	12	N	N
	Bob	47	M	lung	5	N	N
	Ruth	70	F	Colon	7	Y	N
	Stuart	48	M	Sarcoma	*	N	Y
	Joyce	80	F	Breast	*	N	Y
	John	68	M	Prostate	*	N	Y
DISRUPTION	Mark	45	M	Lung	16	N	Y
	Joan	55	F	Breast	*	N	Y
SHIFT	Angela	45	F	Ovary	6	N	N

Key:

* and scores in red indicate high risk scores on the Edinburgh Depression Scale (EDS)

Participant highlighted in blue had a confirmed ICD diagnosis of depression

Reference names are not the participant's real names

M = male, F = female; N = no, Y = yes

three biographical categories. The deviant categories of Biographical Disruption and Shift both contained people of a younger age (45-55 years), supporting Bury's (1982) hypothesis that life stage may predict an adverse response. However Stuart and Bob were also in their 40s but were in the Biographical Flow category. Any relationship between disruption and age is therefore not a straightforward one. Both participants in the Biographical Disruption category had a high risk score on the Edinburgh Depression Scale (EDS); however a number of people in the Biographical Flow category also had high risk scores. Sex, tumour type, living alone and hospice attendance did not seem to predict biographical category. Whether patients were identified from primary care lists or from palliative care clinics also did not predict biographical status.

The life-narratives in this analysis were constructed by me based on my stated theoretical perspective; they are biographical, not autobiographical. It is therefore unclear to what extent the reported life-narratives were part of the lived experiences of individual patients. There was no evidence that individuals consciously sought to construct or maintain a life-narrative. I felt that the identified categories of Biographical Flow, Disruption and Shift described distinct phenomenological experiences. However I was concerned that they categorised outcomes rather than offering an explanation of processes or experiences.

There are already a number of other descriptive accounts of distress within the literature: for example, the spiritual health literature describes distress associated with a search for meaning. However the work has not yet translated into effective clinical interventions (McClain et al. 2003), and I was concerned that the descriptive account in this chapter may suffer the same limitations. I therefore proceeded to a more detailed analysis of the content of the narratives, in order to seek to understand why the described events occurred. In the next chapter I will describe the holistic-content analysis which sought to develop greater depth of understanding and hence offer insights into the potential for clinical practice.

Chapter Seven: Results - developing the model of Self Integrity

7.1 Outline of Chapter

In Chapter 6, I described how biographical patterns were associated with emotional experiences. I also raised concerns that biography was not part of the lived experiences of individuals; there was no evidence that people continuously sought to construct (or reconstruct) a coherent life-story or narrative. I argued that a biographical account could not adequately explain experiences and thus offer insights into clinical care.

In this chapter I describe the results of a holistic-content analysis of the data, which aimed to develop a deeper understanding of the variation in individual experiences. I will begin by describing the key themes arising from the analysis. They revealed that life experiences, including illness, impact on the aspects of themselves which mattered most to people in the study (what I have described as their 'core-self'). Threats to the core-self from life events led to emotional disturbance; people responded by seeking to address the emotional upset. Drawing on those findings, I propose a new model to explain distress and wellbeing in people with terminal cancer: the Self-Integrity Model.

7.2 Overview of themes arising

Four key themes were identified from the data: the Core Self; Threats; Results of Threats; and Balances. Table 7.1 gives further detail of the sub-themes identified for each. In the rest of this chapter, I will discuss each theme in turn and hence finish by outlining the model of Self-Integrity.

Table 7.1: Summary of key themes arising from the analysis

THEME			
CORE SELF	**THREATS**	**RESULTS OF THREATS**	**BALANCES**
Being & Doing Competence Family	**Threats to...** Physical Integrity: (Tiredness, failing body, alien tumour, alien body) Personal Integrity: (Worth, dignity) Integrity of worldview: (Expectation, fairness) **Threats from...**	**Emotional response:** (Distress, anger, fear, frustration, loneliness, depression) **Reflective response:** (why me, why, uncertainty)	**Emotional:** (Release, activities & constraints; being cared for & personal integrity) **Reflective:** (Meaning, diagnosis, shared narrative) **Effects of core-self**

7.3 The Core Self

The importance of the 'self' was a key theme identified from the start of the analytical process (see appendix A7). In each interview, people both described and revealed elements of themselves and their lives which *mattered* to them. Sometimes people stated what was most important to them: either unprompted, or in response to a question from me. Other issues were revealed as important in people's accounts: through the use of language, emphasis, mood when speaking, or simply through repetition. Aspects of the self which mattered most to people were found to be central to understanding people's experiences, including emotional wellbeing and distress. I have therefore referred to them as an individual's core-self.

Having identified all references to aspects of the core-self for each participant, a cross case comparison revealed three sub-themes: Being & Doing, Competence and Family. These sub-themes were evident across all biographical categories: Flow, Disruption and Shift.

7.3.1 *Being & Doing*

Case study: Peter

I will begin my exploration of the theme of the core-self with two case studies. The first is Peter, a 62 year old man with metastatic prostate cancer who lived alone and whose entire interview-narrative was underpinned by his account of being a fell-walker. He described a life-time spent fell-walking; his animated speech making it difficult to follow the complex sequence of events, either at the time or on transcribing the recording. However his animation also underlined the importance of fell-walking to him.

> Peter: *"Well I would go the whole of the Langdales with the [name of group] fell walkers. I mean my first walk was Keswick to Buttermere! It's about 16 miles and about four and a half thousand feet of ascent. And if you haven't got to Scarth Gap by a certain time, you just go down...But you've got to have the wind in your sails to do it. And I used to take parties up – group of mates and we'd go up and along ...And I did the Lakeland Four 3,000s in 1971 in however many hours, 19 hours or something. The certificate's in the [cupboard].... But after my ileostomy, which was in Feb 1986, I went back to*

> *work. 18 months after that – August 1987 – I went to Austria again, and did the* [inaudible: another name]. *12,000 feet up. A month after that, I did the C marathon. Then I went back to do - 1988 or 89 - I went back and did the Four 3,000s again. In 15 hours 50 minutes. That was 1990. And the last time I did it in my boots was 16 hours 55 minutes. And I used to phone outside the digs in Keswick – 'Yippee I've done it!' The whole street would have heard me quite honestly. It was one of those open little kiosks things. And the euphoria. I mean, I would come in, have a chat with [my friend] – have our cup of tea and sandwiches – walk back to the digs, have a shower, have a natter and we'd go out again, into Keswick, to see the rest of them coming in!"*

His account of euphoria revealed '*doing*' fell-walking as something that mattered to him; and therefore a part of his core-self. However his illness had prevented him from fell-walking, and indeed limited his mobility even over short distances.

> Peter: *"I mean it was difficult moving, difficult moving about. You've got this ache, pain, deep inside you. Pain. And I was aware turning over in bed. Deep inside you. And. I felt as though I was stooped. I was always 5'11" and eh, I've always had a spring in my step."*

But he revealed that the act of 'doing' wasn't the only thing that was important to him. He also spoke of meeting Harry Griffin, the author of a book on fell-walking that Peter had shown me earlier in the interview. The animation in his speech, his face, and his body language at that point all revealed a sense of empathy with a man who he also deeply admired - empathy given that both were accomplished fell-walkers.

> Peter: *"And walking down the road, I saw a car with Harry Griffin on the side. So I said, 'Do you mind if I take a photograph of you?' And he said, 'I'll charge you!' So we got talking and I told him where I'd come from and it was about 22 miles that day. So he said, 'Would you like a lift?' So I got in the back of the car and we drive down this track into Coniston and they dropped me off!"*

There was no sense of regret in his descriptions of his walking days; but simply pride, enthusiasm and pleasure from reminiscing. Thus his animation when talking about his previous walks and his empathy with a famous fell-walker indicated that *being* a fell-walker, including a recognition by important others that he 'belonged' to the 'group' that is fell-walkers, was an essential part of what mattered to him – his core-self.

Confirmation of the importance of this sense of being a fell-walker was provided by his account of a conversation with his oncologist, in which he felt that his doctor dismissed his fell-walking and thus undermined his sense of self. The conversation took place shortly after Peter had described how his new treatment regime was improving his mobility.

> Peter: *"I mentioned to [my doctor] that I had walked down to [place]. 'Yes I know you were a fit man,' he said, 'but unfortunately what you have likes bones'. Do you know Dr X? He was cold... He didn't seem concerned about what I want to do or what I had done. He just* [gestures] *out of the way, that's gone."*

Peter was clearly distressed by his doctor's response. My analysis suggested the distress resulted from the failure of the doctor to acknowledge Peter's core-self; and indeed that his doctor's actions threatened Peter's core-self.

Although less prominent in his account, Peter also revealed a second area of his life which mattered to him: his work. Again, he described both the importance of doing and being: doing things well at work, but also being part of a team and respected for his work by the company directors.

> Peter: *"I've worked in* [company name] *for over seven years...I've never had a sick note in that time...I wasn't an accountant but I worked in accounts... I'd do the cheques and put them on the system. Go into their file and match it all off...And that's how I went to Manchester, otherwise I'd have been redundant. My two colleagues who I worked with in accounts, they were redundant...I used to finish work at half past 6. Instead of 5 o'clock. I just put the hours in...And I was on the 4th floor with the directors. Well one of the directors left and...I would have been by myself on the 4th floor because the board room was on the 4th floor and the storage cupboard for the stationery. ...But [Mr C] and [Mr B] – well [Mr B] complained. He had shares in the*

> *place ...And we often had boys' talks – chats in his office. Or go in the post room – pass the time of day and we got on extremely well."*

Common links between these two aspects of himself (fell-walking and work) included a focus on competence (and recognition of competence by others), and belonging. These themes were also identified in other accounts, as described below.

Case study: John

John was a 68 year old man with prostate cancer whose interview account revealed a number of strands to his core-self. Much of his interview-narrative was about his work: his career as a researcher, which had also shaped his life outside of work. He revealed the importance of *doing* research through his account of what he had done and what he planned; but also his sense of *being* a researcher, in his pride and animation in describing who he was.

> John: *"Because there's an awful lot of research that I want to get done...My last few years at the University I switched from what I was doing, which was electron-microscopy, and became very interested in family history. So I was spending an awful lot of time in the library, researching. Because there were a couple of books I was hoping to write...And I've got my memoirs! Which I started writing about 10 years ago ...I keep telling my eldest so. I said, 'You better not get rid of all this research material!' There's a room back there which has got about 12 filing cabinets all full of stuff...[Have my] priorities changed? Not in terms of the research or what I want to accomplish. I still want to accomplish them."*

However he also spoke of his role within his family: of the time he had spent nursing his wife before she died, and his role as father and grandfather.

> John: *"But you see I lost my wife in 2001. She had terminal cancer. She had, she was very bad, All her lungs were filling up and everything. And erm, so. That was one reason why I did take early retirement as well - looking after her those last few years."*

> John: "*You've probably gathered, I was born in the States. And the rest of my family are over there... [But] this is my home. I have my older son, who isn't married and lives at home. Then I have the next boy down - he's married and has a couple of children. They're not too far away either. And then I have the youngest son. And they've got three children. So we've got grandchildren and they're always a joy, of course, to see...But I do worry that I don't. I wish I had more for them...My son's been doing [the household jobs]. What I do feel, I do feel guilty. I think I could do more and I'm letting my son do it. I do feel guilty about that. Because I know I can go out there and do those dishes, and yet I might just leave them. Probably out of sheer laziness, not necessarily that I can't do it. It does. Alright my back does ache if I stand up, but that doesn't mean that I can't do it...We have a great grandson who visits us...But things are a bit different there...I think he's a bit concerned as to why I don't, I can't get down on the floor and play with him as much as I used to. That bothers me. I wish that I could give him more attention. Well I can't get on the floor and play with him anymore that's for sure.*"

His frequent references to his family and his role within the family revealed this as an aspect of his life which mattered to him: his core-self *being* part of a family, and *doing* things for them.

7.3.2 *Competence*

The emphasis on both being and doing in Peter's and John's accounts also reveal the importance of being *capable*: both in terms of being able to do, but also in having their competence recognised. Competence was a theme seen across the interviews, and in all biographical categories. Further examples are given in Box 7.1.

Box 7.1: Examples of the theme of 'Competence' from the data

Angela*:

"I've worked all my working life…I started work in [place] when I was 17 and I worked there until this happened. I was the oldest; a lot was expected of me and a lot extra was put on me…And I was so used to helping other people. The amount of people I've helped in the past through work."

Nora:

"I've always coped a lot on my own because I've had to bring the children up on my own."

Marjorie:

"I very rarely went to the doctor. I did have a gallstone operation and I went to the hospital and what have you. It didn't particularly bother me. I just picked myself up and got on with it….I did retire from work on stress. But that was understandable. I'm not normally that sort of person."

Mary:

"I've always been on my own anyway. My husband died very young so I had to bring the boys up…Rely on myself and nobody else…I was taught by my parents to fight and overcome things… So I think basically that's what keeps me going – my upbringing…My parents…they taught me well: how to be strong and not to run away from problems. To face them."

(* Biographical Shift; ** Biographical Disruption; All others = Biographical Flow)

Box 7.1 (continued): Examples of the theme of 'Competence' from the data

Ruth:

"I'm very well really. I go out a lot. I do my shopping. I clean my house. And I still feel that I can clean from top to bottom. So you know, I'm a well person really."

Stuart:

"And if I plan something, I want to achieve something in six months time, I will achieve it."

Joan**:

"So I just like try to treat life as normal and, like, everything's ok, everything's fine...you know what I mean. For them [her family]. *But maybe I'm lucky and that's just my personality. Because other people all seem to have gone to me and said "I don't know how you cope". You know. It's just me."*

(* Biographical Shift; ** Biographical Disruption; All others = Biographical Flow)

7.3.3 *Family*

Although competence was an important theme revealed in people's accounts, when asked directly what mattered most to them, most people spoke of their family and their role within the family. The importance of family to John has already been described (p119-120). When I asked Ron what was most important to him, he described his role as a husband and father within a larger family unit. This role defined his daily activities and brought him a sense of achievement, as revealed by his rebuttal of others' scepticism of his relationship (see 6.3.2, p101). He also described a sense that being part of a family helped him accept his illness - perhaps with illness as a natural part of ageing and 'making way' for the next generations.

> Ron: *"I think after a time, you just accept [the cancer]...For the simple reason that if your time comes then that's it. There's nothing you can do about it. I'm coming up to 68 this month. Me and my missus have been married for 43 years – 44 this year. We've got eight kids – 20 grandkids. And we've got another grandchild and a great grandchild on the way."*

Others also identified their family and maintaining their role in the family as important to them, and as a motivating factor in managing their illness.

> Nora: *"My family are the most important thing to me...[My daughter] has been so good. That's what I say. You have to keep going. You have to keep going for them."*
>
> Helen: *I've got too much to live for. I've got three sons and I've got five grandchildren. So I've got good things to live for - keep myself strong for."*

7.3.4 *Discussion*

Participants both described and revealed aspects of themselves and their lives which were most important to them. These included roles within the family, at work, and related to other activities such as Peter's fell-walking. Whilst doing things was important, it was also important to people to 'be': including a sense of being competent, but also perhaps belonging - to a family, or a group with a shared identity such as fell-walking.

I have proposed that these aspects are part of what I have called an individual's core-self. Not only are they what people described as important, but they also motivated people's actions (for example see Nora's comments on the previous page), brought a sense of well-being (for example Ron's account of his life as part of his family), and were also the source of distress if threatened (for example, Peter's clash with his oncologist). Indeed further development of my concept of the core-self (in terms of both its nature and importance) was revealed by analysis of other situations in which the core-self was threatened. This is described in the next section.

7.4 Threats to the core-self: developing the concept

People often revealed what was most important to them through their account of times when these aspects were threatened, either by their illness or other life events. Analysis of these threats offered further insight into the nature of the core-self whilst adding further weight to the importance of the concept as fundamental to an individual's life and well-being. By combining analysis of the core-self outlined in section 7.3 with the described threats, I was able to better identify three key elements of the core-self: physical integrity, personal integrity, and the integrity of an individual's worldview. (Integrity was used to refer to 'completeness' rather than its alternative sense: that of "a moral judgement of innocence or freedom from moral corruption" (Oxford English Dictionary 2006). These three elements are described below, through a consideration of the effect of the threats on them.

7.4.1 *Threats To...*

Physical Integrity

The physical effects of cancer and its treatment were revealed in all 19 interviews. The effects of impaired mobility on activity have already been described in the accounts of Peter (p117) and John (p120). Others spoke of *tiredness* and a *failing body*. Descriptions of tiredness were commonly qualified by its effects on people's ability to do things they wanted and needed to do. This was part of a wider sense of their bodies 'letting them down', described by Joyce.

> Joyce: " *I found that I wasn't walking as well as I had been. And it bothered me because I thought, you know, I want to go the toilet, I want to do my own things...It's all just fallen. There's no muscles there at all. And it's numb... Not pleasant.* "

However some spoke of a threat directly from the physical effects of their illness on their body, rather than its impact on what they could do. They described a threat from the presence of an *alien tumour* in their body. Marjorie spoke of the very visible reminder of the presence of her cancer (malignant melanoma). Helen's account of her surgeon's attempt to remove her liver metastases also revealed her sense of the tumour as being 'not part of her'.

> Marjorie: *"The trouble with this specific cancer is there are lumps appearing all the time all round my body.... Every few minutes there's new lumps appearing in different places. Because with breast cancer or something, you can't see the cancer spreading...It's a constant reminder cos you've only got to look down and see."*
>
> Helen: *"I was disappointed over that one. Because I felt as if he'd of done that – <u>cut that piece out</u> – I would have been <u>whole</u> again. But, it wasn't to be."*

However others spoke of how their illness revealed their own body to be the 'alien thing'. Helen had described that she had a sense that there was "something wrong" with her before she was finally diagnosed with colon cancer; her diagnosis was not a complete surprise. However for Mary, the diagnosis of recurrence of her lung cancer came out of the blue.

> Mary: *"But the actual shock for me was, I had my lung out at the beginning. I thought that was the end of it. ...And was doing great with two thirds of the lung gone. And then I put all this weight on because I stopped smoking and I wasn't exercising, so off I goes back to the gym...Doing great Joanne, smashing. And then went back for my normal check up and they weighed me and [were worried by] all this weight [I'd] lost...And I was arguing the point: I've been on a diet. I've been running in the gym. So I've lost this because I wanted to lose it...Felt brilliant. And then they come across with the results that it had gone to me bones. They showed me all the big black spots."*

Her awareness of her own body told her she was getting better and fitter, losing weight through her exercise. The scan results showing "*big black spots*" of cancer in her bones came as a shock; not least because she had interpreted her own body differently. She subsequently described finding it hard to distinguish between 'normal' aches and pains and pain indicating the cancer had spread further. Others described similar episodes of being 'tricked' by an *alien body* that was not as they expected.

Threats to physical integrity came not just from the limitation on *doing* things, but also by causing a sense of *being* different or not what they expected. This revealed physical integrity as an important part of what mattered to people: part of their core-self.

Personal Integrity

Having identified physical integrity as a key sub-theme of the core-self, I re-conceptualised the elements of the core-self described in 7.3 as the 'personal self': the non-physical aspects of the self. Analysis of peoples described threats reinforced the importance of the previously identified theme of 'a family role' as part of the core-self. Revealed threats also emphasised the importance of a sense of competence. For example, Joyce's account of the delay in diagnosing her with spinal cord compression from metastatic disease revealed that she was not concerned with the threat to her physical health from the delayed diagnosis. Instead she described how her doctor's failure to acknowledge her as a competent and active woman served as a threat to her personal integrity, and her sense of herself as a "*fit*" and competent woman.

> Joyce: "*I saw three doctors four times. And by the last time I saw them, I could hardly walk... My own doctor let me down terribly I think. When he knows I was a fit woman...I walked in on [my husband's arm] and a stick. Surely to God he could have seen there was something radically wrong there. When I went in I didn't sit down, I fell down... But it rankles with me terribly. It hurts me terribly...To let me go all them weeks.*"

Self-worth was also revealed as a key aspect of personal integrity. People described being treated differently by others. Mary spoke of being "*stained*": the *stigma* of being ill constituted a threat to herself. Jim and Helen spoke of their illness as a 'judgement', undermining their sense of worth. Finally Joyce and John spoke of the threat of illness through the threat to their dignity and hence their self worth (see Box 7.2).

Box 7.2: Threats to self-worth

STIGMA	Pat: *"People treat you differently. And they come through the door, you know, like Uriah Heep. 'Oh how are you?' 'I'm fine, I'm fine' You're alright – it's not catching I haven't grown 2 heads."* Mary: *"There's lots of people [living with cancer] can't explain and get it off their chests. They feel like they've let their families down, let their children down. Because [pause 2 seconds] they're stained aren't they? When I say stained, we can't, don't have the energy to do what we used to do."*
WHY ME	Jim: *"Well the only simple way I can describe [the depression] to you, is say I look at somebody that I know that is not of the best, and I say well why did it have to happen to me?"* Helen: *"Why me? That's all I could ever say. When you see these horrible people going round the street, nothing happens to them, you know Why me?"*
DIGNITY	Joyce: *"You know when I was lying in the hospital and I had to be washed and dressed.* [sigh] *When you've never had things like that. Now I was 77 when this happened. And a fit 77...And you've got young girls washing you. Oh it's undignified...I'm very grateful to them, but it's not nice."* John: *"I mean letting the nurse when I was at the hospital help with the shower and this and that. I mean, there'd have been a time when no way. But that attitude - I've certainly lost my, what shall I say, shyness. The shyness or anything like that. That has gone through necessity"*

In summary, personal integrity was identified as those aspects of being which were not purely described in terms of a physical body. They included aspects of *who* I am (role and identity e.g. competence) and *why I matter*. The importance of these aspects of the self was further highlighted by people's accounts of threats to them, which were associated with distress.

Integrity of world view

The third aspect of the core-self identified in the data was their understanding of the world: their world-view. John spoke of the threat from altered *expectations*:

> John: *"I more or less expected a long life. Because my mother was 96 when she died. My great grandmother was 98. So there is a longevity. ...So it was a bit of a shock in terms of that"*

Others referred to a threat to their sense of *fairness*, in a similar way to the 'why me' questions described in box 7.2.

> Mark: *"But I went through life thinking I play hard, I work hard. I used to cycle everywhere. I went for what I thought would be the healthy lifestyle. And then this happened.... Well I look and see big fat blokes smoking and not doing any exercise and all that. You know what I mean! And I look at them and go oh. I did look and say. I looked after myself"*
>
> Joyce: *"Now I don't smoke, I don't drink. I make me own food in the kitchen - I don't buy packets of whatever. And I say - why? When you just get people who are abusing themselves every day of their lives. And they just sail through life. Doesn't make sense."*

Thus individuals' core-self included reference to aspects of the world outside of themselves, but which in turn impacted on them. My analysis therefore described a third element of the core-self which may be threatened by illness: the integrity of an individual's world-view. Again, threats were associated with emotional distress, underlining the importance of these aspects of life to the individuals concerned.

7.4.2 *Sources of threats: Threats from...*

Although most identified threats resulted from the direct or indirect effects of people's illness (as described in the account presented), participants also spoke of other life events which contributed to these effects. Ruth described how an upset in the family had caused her more problems than her illness, whilst Helen emphasised the impact of her husband's suicide a few months previously. These effects are perhaps summarised in an email from John, sent to me after he had received the invitation to join the research study.

> John: "*I have been asked by Dr X to take part in your Research Study of patients with cancer. This I have agreed to do and will send back my acceptance and fill in the questionnaire, but there is one point I would like to make, something which you no doubt are well aware of.*
>
> *Individual circumstances have a large bearing on how one interprets and answers questions. In my case I lost my wife in 1999 and then started to live on my own. I was just about settling down when I had a stroke in December 2003. After several months in hospital I had to start all over again trying to adjust to living on my own with the added problem of being partially disabled, and then to be told I had cancer. Please don't misunderstand, I will answer any questions you care to ask, but I feel I had to make this point clear.*"

In his subsequent interview, he also described:

> John: "*This is where I'd like to emphasise to you, the main cause of my depression is the fact that I did lose my wife. And the other is the fact I had the stroke, and the after effects of the stroke. It's not the diagnosis of the cancer on its own that's made it worse. It's the diagnosis of cancer on top of the other things that made it slightly worse*"

Other researchers have described how life events other than illness are often the primary cause of disruption. For example Ciambrone (2001) described how the impact of domestic violence and drug use were more disruptive of biography than a diagnosis with HIV/AIDS.

7.4.3 *Discussion*

Based on my analysis, I have proposed a concept of the core-self consisting of the aspects of themselves which mattered most to people. These were directly described in people's accounts of what was important to them, or revealed in their narrative especially through descriptions of the impact of threats to these core aspects of their lives. Three elements of the core-self were identified: physical integrity, personal integrity and the integrity of world-view. There was arguably some overlap in these elements: for example threats to physical integrity through the presence of an *alien tumour* may also have added to an individual's sense of their worth being undermined. The presented categories are intended to illustrate the breadth of the concept of the core-self, rather than being viewed as clearly defined distinct entities.

Life events, including but not exclusively a terminal cancer diagnosis, threatened the core-self. The associated distress provided further evidence of the importance of these aspects of themselves to each individual. The experience of threats to three elements of the core-self was common across all three biographical categories; it was the response which varied. In the next section, I will focus on a more detailed account of the impact of these threats on people before describing how people dealt with them; allowing the majority to maintain Biographical Flow.

7.5 Results of Threats

Responses to the threats described could be grouped into two categories: emotional and reflexive (narrative) responses. Each is described below.

7.5.1. *Emotional response*

The emotional reaction to a threat to the core-self was primarily one of distress, which was described in a number of ways: as feeling 'bothered', anger, frightened, frustrated or lonely (see Table 7.2) Some spoke of depression, but described something qualitatively different to a biomedical account of depression. Distress and depression were associated with threats to the core-self. For example, Joyce was bothered because she could not continue to do what she felt she needed to do in her role as a wife and mother. Nora spoke of her fear resulting from the threat to her physical integrity, with her body no longer being 'her own'. Mark and John spoke of the impact of their sense of loneliness: a loss of a sense of being part of a bigger world and hence a threat to the integrity of their world-view and their self-worth (personal integrity). The threat to the core-self underpinning each example of distress is described in Table 7.2.

Finally the cumulative effect of dealing with both threats to the core-self and the emotional consequences was described as a feeling of exhaustion.

> Helen: *"It wears you out, it really does...[Sometimes] I come home and go 'How can I laugh...I have a little five minutes saying, 'Oh sod it. I'll do what [my husband]'s done."* [referring to his recent suicide]
>
> Mark: *"But you know, it just feels like an uphill battle - one step forward, two steps back."*
>
> Mary: *"But its like a drain, it drains you...I feel with my cancer it's hard work. Because you don't always have the energy."*
>
> Stuart: *"I've been having a lot of trouble sleeping. So during the day, I'm really tired. Get depressed and I've got no motivation to do anything."*

Table 7.2: Examples of emotional disturbances described by participants following threats to the core-self

Response	**Description**	**Threat to core-self precipitating distress**
Distress	Peter: *"But I wasn't able to go in because fatigue, fatigue...And it was so distressing because you wanted to work but weren't able to. And to let my colleagues down."* Joyce: *"I came off the steroids and I found that I wasn't walking as well as I had been. And it bothered me because I thought, I want to go to the toilet. I want to do my own things."*	Personal integrity: competence Personal integrity: competence
Anger	Helen: *"My husband's suicide] made me angry. Because I though I've fought to stay and yet you've chosen the coward's way out...And I get angry with God. You know, 'Why me?'"* Linda: *"Oh yes, very angry. I don't know who I've been angry with. Probably me. The fact it came back."*	Personal integrity: worth; World-view: fairness World-view: fairness
Fear	Nora: *"Anxious. Because you feel as though. I can't explain it. You feel as though your whole inside is not your own. And you start getting panicky for no reason."*	Physical integrity
Frustration	Nora: *"But I think some of the frustration is because I can't do some of what I want to do."*	Personal integrity

Response	**Description**	**Threat to core-self precipitating distress**
Frustration	Jenny: *"Very frustrating...Because I don't want to just sit back and let someone do it for me. I want to do it myself...Sometimes it makes me really bad tempered. It really does."*	Personal integrity
Loneliness	Mark: *"But yes, you do feel rejected as well I suppose."*	Personal integrity
Depression (blackness)	Mark: *"But yes you do get depressed. You feel black. I mean it was dark days for a while...My wife says I was suicidal."* Peter: *"The day the bone scan was done, that was the blackest day of my life."* Joan: *"But if I start to think deep, well that's when you start to get depressed...It's just so scary when you're first diagnosed...And you're depressed and go into this cocoon waiting for the result."*	Mixed Personal integrity Mixed

Considering Depression

Many of the participants spoke of times when they had felt depressed. However there was a difference in the accounts of depression offered by those in the Biographical Flow and Biographical Disruption categories. People in the Biographical Flow category spoke of transient periods of 'feeling depressed' as a result of the threats previously described:

> Stuart: *"But since they've told me, you know, it's terminal and that, you start thinking about how long you've got and what you've achieved and what you haven't achieved and yeah, it does get you depressed. But not. As I say 30% of the time not 90% of the time, you know. Because I do forget it as well"*
>
> Helen: *"Oh yes, I've been through depression. But...it may last half a day, a day at most"*
>
> Jenny: *"[When I feel down], I feel sorry for myself. I've got to be honest...I won't let it last more than a day or so."*

For many, episodes of depression were seen as something to be expected. Joan described that her depression was understandable *"because I'd been through so much"*. Stuart described:

> Stuart: *"I'd rather not have [bouts of depression] but you know I think it's just bound to happen you know. If someone's told you you're going to die soon, I think everyone would get a bit depressed wouldn't they? They'd think about it and then start getting a bit depressed. So, it's something that I expected to be. You know. Just start of the thing, that I expect to get depressed...But I think it'd just be, it's just a part of accepting, accepting that you're going to die."*

This final comment, that depression was not only something to be expected (normalised depression) but something which was necessary, was also described by others:

> Pat: *"I've suffered from depression all me flippin life. I think it's been a way of combating it."*
>
> Jenny: *"You feel sorry for yourself because you've got cancer...But I think it's just like a release valve."*

> Mary: *"But I'm only depressed for a day or two. Or for that night or morning. And then I can rise above it...It's not depression. It's a quiet mode of deep thinking."*

Mary spoke a number of times of feeling depressed, and like others emphasised that she felt it was both normal and necessary. She recognised that others might not agree with her assessment; and stated explicitly that although she felt depressed at times, it wasn't depressed in the medical sense.

> Mary: *"People would probably say as a professional that it's not working for you because you're still feeling this way. But it works for me. I don't think I am depressed in the medical terms. But I do think I'm worried."*

Interestingly, Mary was the only interview participant who met the ICD criteria for depression (as assessed by the CIS-r) at the time of interview. Yet her description of depression is more closely related to Gut's (1989) account of 'productive depression' than a pathological model. She described her depression not only as 'normal' or to be expected, but also as having a purpose. Feeling depressed prompted a withdrawal from normal activities allowing time for reflection, as was also described by Stuart.

> Stuart: *"[When I'm feeling down] I'll often go for a walk...down the river front and that. I like just being on my own sometimes...It just gives me time ...There's always something going on in here. So it's good to go for a walk...And then there's no one disturbing your thoughts... And it just feels good to be on your own for a couple of hours or whatever."*

There was evidence that both withdrawal and reflection were necessary to support a process of dealing with the threats to the core-self and hence maintenance of Biographical Flow. This idea is discussed further in section 7.6.1 (p140).

The two people in the Biographical Disruption category both described having suffered from depression, but their accounts were different from those in the Biographical Flow group. Mark's symptoms of depression appeared to have been consistent with the ICD definition described earlier in this thesis, including low mood, reduced pleasure, fatigue, and recurrent thoughts of death (see Box 4.1, page 64). Throughout his account, he revealed that his depression was a result of the build-up of physical and emotional exhaustion dealing with the effects of his illness and the threats to his personal integrity, including a sense of being "*rejected*". (See page 105-6 and quotes below).

> Mark: *"I think it was a slow build up – it was a slow build up. I went through the first lot of chemo...Then I got that infection half way through the last lot of chemo and that really. I couldn't eat, I couldn't talk about it you know. I mean I was cooking food but I wasn't hungry. I was hungry but couldn't eat it...You've got no energy...*JR: *You said yourself having cancer has made you feel depressed. Could you tell me how that feels?* Mark:*...you do get depressed – you feel <u>black</u>. You feel, 'why me? And you can't do things. I was <u>angry</u>, very angry – extremely angry... I mean it was dark days for a while you know... But yes, you do feel urm – rejected as well...But er you can't make it out - some people, they don't wanna know. They didn't wanna know. Now whether it was the Big C, or they live in the ancient days of you don't talk about it. Like HIV – on no, don't go near it. I mean you can't catch cancer!"*

Joan described a similar process of threatening life events leading to physical and emotional exhaustion and ultimately an experience that was diagnosed as depression. For both, it seemed that the disruption to on-going daily life occurred as a result of the exhaustion arising from threats to the core-self. The combined experience of exhaustion and Biographical Disruption appeared to overlap with biomedical descriptions of a presumed pathological state of depression. Perhaps the experience of 'depression' is better conceptualised as emotional and physical exhaustion, precipitating an inability to continue living normal life and hence Biographical Disruption. Biographical Disruption is the effect described by an external observer, whilst depression is the lived experience of the individual living through that disruptive phase. Yet it is also important to note that for both Mark and Joan, being diagnosed with depression by their doctor (albeit based on a biomedical account of depression) was an important part of their recovery. This issue is discussed further in 7.6.2 (p143).

There was some overlap in the accounts of depression from people in both the Biographical Disruption and Flow groups. Across the two categories, the experience of a cluster of symptoms described as depression appeared to result from threats to the core-self. However the symptoms were only transient in the Biographical Flow group; and, for some, were productive. Periods of low mood or low energy prompted activities which supported a subsequent improvement in mood and hence continuity of life-narrative. Those already described included going for a walk or having 'time out' on your own. Helen spoke of spending the day in her pyjamas, reading a good book and having a reason to avoid seeing other people. Then the next day, she could carry on as normal. Thus periods of depression were an important *"release valve"* (Jenny, see page 134); necessary perhaps because living with terminal cancer, and maintaining Biographical Flow, was an exhausting process.

For people in the Biographical Disruption group, depression symptoms were associated with threats to the core-self but were ultimately debilitating rather than a release. Indeed I have proposed that 'depression' describes the lived experience of individual's undergoing Biographical Disruption. Thus treatment of depression in these circumstances may benefit from a focus on the disruptive events rather than simply a pharmacological treatment of a presumed pathological state. In addition disruption occurred in people who were already physically and emotionally exhausted; perhaps any 'productive depression' mechanisms had been overwhelmed. This suggests it may be possible to identify points of high risk for individuals and within the cancer treatment pathway that warrant extra attention in order to try to prevent Biographical Disruption, or debilitating depression. Again, it is worth noting that even though the depression of Disruption was debilitating, it was ultimately productive in that it prompted the introduction of a supportive care package for both individuals (see 'Diagnosis', p144).

7.5.2 *Reflective response*

Emotional responses to threat were universally described. However some individuals also described a reflexive response: a questioning or search for meaning. Threats to their personal integrity led to a response of "*why me?*" Threats to the integrity of their world-view led to a response of simply "*why?*" Some examples are shown in Table 7.3. Like the emotional responses, this reflexive response was usually transient.

Table 7.3: Illustrating reflective responses to threats to the core self

Theme	**Example**
Why me?	Helen: *"I just wish I'd never had it. Why me? That's all I could ever say."* Jim: *"And I say well why did it have to happen to me?"*
Why?	Jim: *"And I used to say, 'What the hell did you have to go and leave me for?' Why couldn't you wait?"*
Uncertainty	Stuart: *"My body's tired but my mind just keeps going, thinking about all different things... From when they told me, you start thinking about how long you've got, how you are going to die and all that. So the depression sort of come on since then."*

7.5.3 *Causal relationships: narrative & emotional responses*

It is difficult to say from the interview narratives in this study which came first: an emotional or narrative response. Psychological theory would predict that emotional distress results from cognitive upset (Beck 1976), and some interviews revealed evidence of this:

> Stuart: *"Thoughts that keep going over in my mind and that's when I get depressed thinking about things cos there's nothing I can do to change things."*

However for some people, emotional states preceded (and therefore influenced) the reflective process:

> John: *"There have been occasions, sometimes lying in bed, earlier on, when you had certain feelings and this and that perhaps you know and pains and this and that. You know. That, you may perhaps start dwelling on, well you're going to die and you know it."*

The data revealed negative emotional responses in most people, but a reflective response in only some people some of the time. This apparent difference may have been an artefact of the research process and the emphasis of my interview schedule, rather than reflecting a 'real' difference in lived experience. Yet distinguishing whether psychological processes or an emotional upset was the primary event is clearly important given the implications for treatment. A psychological theorist would advocate that treating emotional distress depends on dealing with the thoughts (Beck 1976). The data in this study suggested that, for some at least, focusing on psychological or cognitive factors *may* not always be effective since the emotional disturbance was the cause of the thought disorder. There was evidence supporting the need for interventions focused at an emotional level rather than only a narrative or cognitive level.

7.5.4 *Discussion*

In this section, I have demonstrated that threats to an individual's core-self resulted in emotional distress; and for some, a reflective response of seeking meaning. Some described periods of depression as part of that distress. However experiences were usually transient; and often seen as normal and even helpful. For a minority, threats led to physical and emotional exhaustion precipitating a period of Biographical Disruption and a more profound period of depression. I proposed that depression may therefore be understood as the lived experience of emotional and physical exhaustion associated with a loss of ability to continue living your life, or Biographical Disruption.

The existing narrative-based literature emphasises a reflexive response to life-events, arguing that people react to events by seeking meaning and to (re)construct a story (Greenhalgh & Hurwitz 1998, Launer 2002, Mattingley 1998). Psychological theory proposes that emotional distress results from cognitive upset (Beck 1976). Both approaches emphasise the narrative or reflexive 'cause' of emotional distress, with implications for treatment. My data have suggested that, at least for some, there is a need for an emotional focus for interventions rather than a purely narrative one.

Whether emotional distress was transient, or associated with the more profound upset of Biographical Disruption, all participants described themselves as 'well' at the time of interview. Biography and emotional well-being had been restored or maintained. In the next section I will address the question of how people were able to do so.

7.6 Balances

Analysis revealed three areas which supported people's ability to restore or maintain emotional stability and Biographical Flow. These were Emotional support, Reflexive support, and the effects of the core-self, and are described below.

7.6.1 *Emotional Support*

Participants described a range of things that they did or experienced which in turn brought positive emotional support, 'balancing' the draining, negative effects described from the threats in the previous sections. Themes identified included active release, reduced constraints, other activities, being cared for, and reinforced personal integrity.

<u>Release, activities and constraints</u>

People spoke of doing things in order to try and control the distressing effects previously described. Helen spoke of the need to release pent up emotion:

> Helen: *"Getting stuck into the house - really scrub the wood. That gets the anger out ...You must cry sometimes. You must...You couldn't hold them in forever. Your body'd explode. It really would.* You've *got to. You must cry."*

Marjorie and Angela described getting pleasure from doing craft activities: both from its effect as a distraction, but also in giving a positive emotional boost.

> Marjorie: *"I worked in a school so I love craft work... I do a lot of card making and that is brilliant because it just takes your mind off you know, when you're busy."*
>
> Angela: *"I sit and do craft...and I get a great deal of satisfaction out of doing it. It's what I always wanted to do and never had the chance because of working and house work - being tired."*

Others also mirrored Angela's emphasis on their experience of *reduced constraints* in giving up work, and having time:

> Stuart: *"I'll often go for a walk...down the river front and that. ...There's always something going on here. So it's good to go for a walk... And it just feels good to be on your own for a couple of hours or whatever."*

> Helen: *"Just some time to sit and relax, to chill out...Sit with your pyjamas on all day if you feel like it."*

A range of other activities were described which brought an emotional 'boost', in addition to some distraction. For Jenny, it was about continuing to go out with friends to the bingo or for a coffee. Ruth continued the pleasure she had always got from gardening. Mark had found new roles, working as a volunteer at a local organisation. Faith was also important in providing emotional support, as well as reinforcing the integrity of people's world view:

> Helen: *"I'm a catholic...You've got to have faith. You've got to believe. Without believing in something, you're lost...It's about being strong."*
>
> Jenny: *"Faith has always been important to me but more so since I got the cancer. And I think it also gives you a comfort."*

Thus people described approaches which provided a balance to the draining effects of threats to the core-self.

Being cared for & reinforced personal integrity

People also described the importance of being cared for, something which was associated with a positive emotional boost. Within the context of my analysis and the model of the core-self, I believe these accounts of being 'cared for' revealed circumstances in which people's personal or physical integrity was supported, for example through emphasising their worth or competence.

> Angela: *"They've been so lovely to me, they've been so gentle. People tend to let you do things in your own time. Which I think is so nice."*
>
> Mark: *"I would say you need people. I got through because of people I could talk to for support. If I hadn't of been married, I don't think I'd be sitting here."*
>
> Marjorie: *"You need a safety net - somebody there."*
>
> Jenny: *"The staff at the hospice are so caring...You don't want sympathy, you want a bit of understanding. Sympathy makes you upset and cr., But a little bit of understanding goes a long way."*

> Ruth: *"In [the oncology hospital] the care is wonderful. The attitude of people towards you. Not sympathy or namby-pamby treatment. But just so nice. The way they treat you. You feel like a VIP...And you were just so special to them. You felt you were the only one there with cancer."*

Most people's descriptions of caring identified the non-narrative aspects of being with others. Touch was an important part of being made to feel cared for, and therefore of supporting the core-self:

> Mary: *"There's something in everyone that will bring them up a bit. Praise is a wonderful thing...Praise and warmth and love. Touch and everything."*
>
> Joan: *"Well anything with touch - aromatherapists' touch. Contact with someone else. When you're depressed. It does, it does lift you a bit."*

Joan emphasised the importance of the non-narrative aspects of care in her account of an ineffective visit to an aromatherapist, and subsequently of her experiences of spiritual healing.

> Joan: *"She* [the aromatherapist] *wanted to counsel me and I didn't want that. I just wanted the therapy. I just wanted to feel."*
>
> Joan: *"And I feel that I'm getting a bit of peace with the spiritual healing...[The cancer support group] got funding for this reiki practice and they're doing it. Now I haven't had it since before I went on holiday and I can feel the difference. Cos it's lovely - that's another thing that makes you feel very serene. And I seen her about three times and suddenly I started to think straight again. Where I'd been chasing like a dog with its tail, I started to feel - I put things in order, slot things in order."*

People clearly described important non-narrative approaches to managing threat and distress. The importance of caring was clearly described in the data. 'Caring' is a term recognised by both health professionals and lay people and regarded as an important feature of health care; however, it remains poorly conceptualised (Lea et al. 1998). Creating opportunities for development of caring therapeutic relationships within health care settings may be at risk in a world where disease-focused evidence-based practice sets the priorities. It is therefore important to develop a better evidence base around the nature and importance of caring relationships. My study offers a framework by which to understand caring as a reinforcement of the core-self. Development of these ideas may support development of clinical practice and training as well as ways to measure the impact of care on the lived experiences of individuals.

7.6.2 *Reflective Support*

I have described how threats to the core-self prompted, for some, a distressing reflective process. However this reflection and search for meaning was also identified as part of the process of coping with threats. People revealed evidence of seeking (and finding) *meaning* in events, often drawing on their pre-existing core-self. *Shared narratives* offered an opportunity to *talk* with others in the search for meaning, but also brought an emotional benefit and a *feeling* of comfort. Medical *diagnosis* offered the identification of meaning for some, including being an important contribution to the imbalance in the two people experiencing Biographical Disruption.

Meaning

Helen's description of how she understood life arguably underpinned her experience of Biographical Flow. She saw her illness as simply 'part of how life is'; and this sense of meaning was associated with 'acceptance' and emotional comfort. Similarly Mary understood her illness as part of life, bringing meaning to her experience and therefore comfort.

> Helen: *"That's the way life goes. It throws everything at you. Sometimes you duck, and sometimes it hits you. When it hits you, it knocks you off your feet. But you've just got to get up and get on with it."*
>
> Mary: *"And the actual idea of having the cancer came as a shock. But I can handle it if I do it my own way. And I am handling it very well...I accept what life throws at me...being ill is a responsibility to yourself. And I accept that responsibility. And I'm responsible for other people [too]."*

Joan offered a different insight into the importance of meaning, describing the comfort she derived from someone else's explanation of the way she was feeling.

> Joan: *"But I went to see this homeopathic doctor. I asked about my energy. I said, 'Can you give me anything for that?' And she said to me, 'You know*

> *you're going to be like a new born baby. You know the way a new born needs sleep all the time.' She said, 'That's because your body's building, new cells...because your body's been knocked out.' And I thought, that's a good way of thinking."*

Diagnosis

A particular example of the positive effect of meaning was seen in the case of the two people diagnosed with depression at the time of their Biographical Disruption. I have already described the case of Joan, whose experience of Biographical Disruption was associated with a diagnosis of depression (page 108). I have questioned whether the cause of her symptoms described as 'depression' may be better understood as the physical and emotional exhaustion arising from threats to her core-self. However the depression diagnosis did allow her access to successful care and support, including treatment with antidepressants. Yet I have already described that a restoration of mood and energy occurred by the third day of treatment.

> Joan: *"So she got me [antidepressants]... And then I took them. Second day and I thought, I'm starting to feel a little bit more energetic. Like I've got a bit more energy. And by the third day, I was feeling a lot better. And I thought, it must have been the depression. Because I'd gone through so much."*

Her rapid improvement cannot be explained by the pharmacological action of her medication: biomedical diagnosis and treatment was not the primary therapeutic intervention. Instead I hypothesise that healing came through a combination of emotional support (i.e. care), and the offer of an explanation for her experiences - the identification of a meaningful narrative. Mark's diagnosis with depression and subsequent referral to a counsellor offered him similar support. The diagnosis helped him make sense of the way he was feeling, and the support from the counsellor was an important balance to the negative effects of living with his illness.

> Mark: *The counsellor told [me I was depressed. She] turned round and said, 'You've been referred to me because apparently you've been depressed.'* JR: *Did you agree? Did you think you were depressed?* Mark: *Yes. I thought. I knew I wasn't right. I thought it's not right this...I was talking to my Doctor*

> *and he told me about the counsellor. And I thought – yeah, I see where you're coming from.* JR: *And how did you feel when [the counsellor] suggested that maybe you were depressed?* Mark: *...How did I feel? I felt depressed!* [laugh] *No I felt elated! Not elated – that's wrong. I felt a bit happier – it was depression and it was getting sorted. Does that sound Irish?"*

Diagnosis and meaning was also important for those in the Biographical Flow category, and related to experiences other than depression. For example, Jenny described:

> Jenny: *"I'll tell you what does worry me. I went to the doctors. It sounds funny. And I said, 'I think I'm getting Alzheimer's. Because my concentration's not the same. And I'll go into a room for something...and forget what I've gone in for....And she said, 'No It's stress. Don't you realise you're under an awful lot of stress?'* JR: *How did you feel when she said it was stress?* Jenny: *I felt better!"*

Within a model emphasising the core-self, medical diagnosis is important but for different reasons than seen with a pathological model of health. Firstly it offers meaning, which brings emotional support. It is also part of a supportive narrative process, but importantly this was a *shared narrative*. This concept and its therapeutic effects are described in the next section.

Shared narrative

The search for explanation and meaning, or even just for tips on how to manage the physical effects of illness, was often described by participants in terms of developing a shared narrative. Reflection was described as helpful in finding meaning; but by sharing that process with others, people gained additional emotional support:

> Pat: "*When we talk – and it's only banter. But you do pick little things up. You know - the coughing - always have a glass of water next to you. They might sound silly little things to anyone else but they're important to you...And then you listen to how they've coped with it."*
>
> Mark: *"It helps – talking about it. Talking. Get people to open up about it. Erm helps a hell of a lot. Well it's helped me. I know how I feel. It's helped me."*

> Marjorie: *"And everyone needs to talk about it...I think you* <u>*feel*</u> *better because you think, well I'm not the only one thinking like that. I'm not the only one crying in the corner...It's more the fact that you don't feel so alone...And you're thinking, God well I'm like everyone else. I think that's what helped me more than anything else."*
>
> Mary: [Talking to me as the interviewer] *"But it does help talking to someone like yourself...Because you feel so alone with cancer."*

Charmaz (1987) described that at times of illness, people become more socially isolated and therefore have to turn to new groups for support. Fellow patients or health care staff are potential sources of such help. She proposed that illness also prompts a greater reliance on other people to support self-definition and self-identity. My work and the earlier study described by Chamaz (ibid) therefore highlight the importance of understanding interactions in the context of the effect of illness on the self. Whilst information giving is a useful part of a narrative process, other non-narrative elements of interactions are also vital to provide the necessary support.

7.6.4 *Effects of the core-self*

The third factor identified as important in balancing threats was the nature of the existing core-self. By continuing to do things which mattered to them, people described emotional benefits which helped to balance out the negative effects. For example Joyce, a woman whose core-self centred on her competence and her family role, described how she tried to just *"get on with it"*, including caring for her husband. Helen spoke of dealing with her illness through strength: being strong was part of her core-self.

> Joyce: *"Before, if someone had said, 'Oh she's got cancer,' I'd think, 'Oh how terrible'. But it didn't hit me like that. I thought well I've got it, what can I do about it? Get on with it."*
>
> Helen: *"I don't like anyone to know...I'll just say nothing. And I think that's my way of getting over things...And that keeps me strong...I think it's just determination...*JR: *And what's seen you through that difficult time?* Helen: *Strength. Strength from me."*

The importance of the core-self was perhaps most clearly described in cases where a release of constraints had allowed people to focus more on the things that mattered to them. The starkest example of this was Angela and the Biographical Shift described in Chapter 6. Interpreting her account from the perspective of the notion of a core-self as presented in this chapter suggests a shift in her lived experience of her core-self (what mattered to her) which allowed a more positive emotional experience. Others revealed similar, although less extreme, examples of altered priorities. Most described a greater appreciation of the world around them with less focus on material things.

> Nora: *"If it's nice, I'll go out in the sun."*
>
> Jenny: *Well you think about things you never thought about before...The first time I got diagnosed, I was stood at the back door and looked at all the different shades of green. Now, you take it for granted. Flowers and everything and the birds...You think more deeper some how."*
>
> Mark: *"And I think now, well heh hey so it's a house! Why do you need to be rushing? I don't run for buses any more! You know – if I miss a bus. Well ok, there'll be another in a few minutes. Don't be rushing."*
>
> Stuart: *"I mean I used to get angry. I used to get upset and narky about things in the past, but now them things don't bother me because they wouldn't be as important to me."*

The question arises whether these accounts revealed a shift in the 'true' nature of the core-self, or a removal of constraints allowing the 'real' core-self to emerge. Certainly some fluidity in the core-self is suggested by Joan's comments.

> Joan: *"I think I have changed. Cos I always worked and everything. I'm the type of person – I thought I would crack up, you know, if I wasn't working. But I don't know how I had time to go to work now. Cos I have the children and the grandchildren. Go to the day centre. I just don't know how I had the hours to go to work. I have changed. Stronger. I think I'm stronger in a lot of ways. From what I've been through...I'm stronger. I can accept things now."*

However I have argued that a threat to the core-self resulted in emotional disturbance, with an implication that stability of the core-self is important. To suggest that a shift in the core-self could be beneficial seems to contradict that idea.

There may be some challenges to the core-self which have a positive effect (leading to a positive shift) and some which lead to a negative effect (and even disruption). However cross-case comparison between Mark and Joan (Biographical Disruption) and Angela (Biographical Shift) was unable to identify what these two groups may be. Alternatively, I would propose that there could be an element of the core-self which is stable, at least over the time scales revealed in this study. However the external presentation of the self (and even its awareness to the individual) may exhibit some fluidity.

7.7 Developing the Self-Integrity model

The findings described in this chapter build on the stated idea of a core-self, defined as what mattered to people. The core-self included the integrity of the physical self, personal self and an individual's world-view; and was described in my analysis as central to understanding the experiences of people with terminal cancer, and especially their emotional health. The emphasis on emotional experiences in identifying what mattered to people placed an emphasis on the self as an 'emotional being'.

The importance of the core-self as defined in this thesis lies in its ability to influence experience and behaviours. Illness and other life events threatened the core-self, resulting in emotional distress. Some also described a transient reflexive search for meaning. Most were able to accommodate the negative effects of the threats through a combination of emotional and narrative support, thus maintaining a continuity of life-narrative or Biographical Flow evident to the outside world. However the data highlighted that continuity comes at a cost. I started this thesis with the words of '*The Silver Swan*' (page viii), perhaps as an alternative reference to Giddens' (1979) description of learning from a 'critical situation'. The analysis in this chapter reveals a further link to the analogy of a swan: where the outside world observes the individual gliding smoothly forward, in reality there is much work going on 'under the surface'.

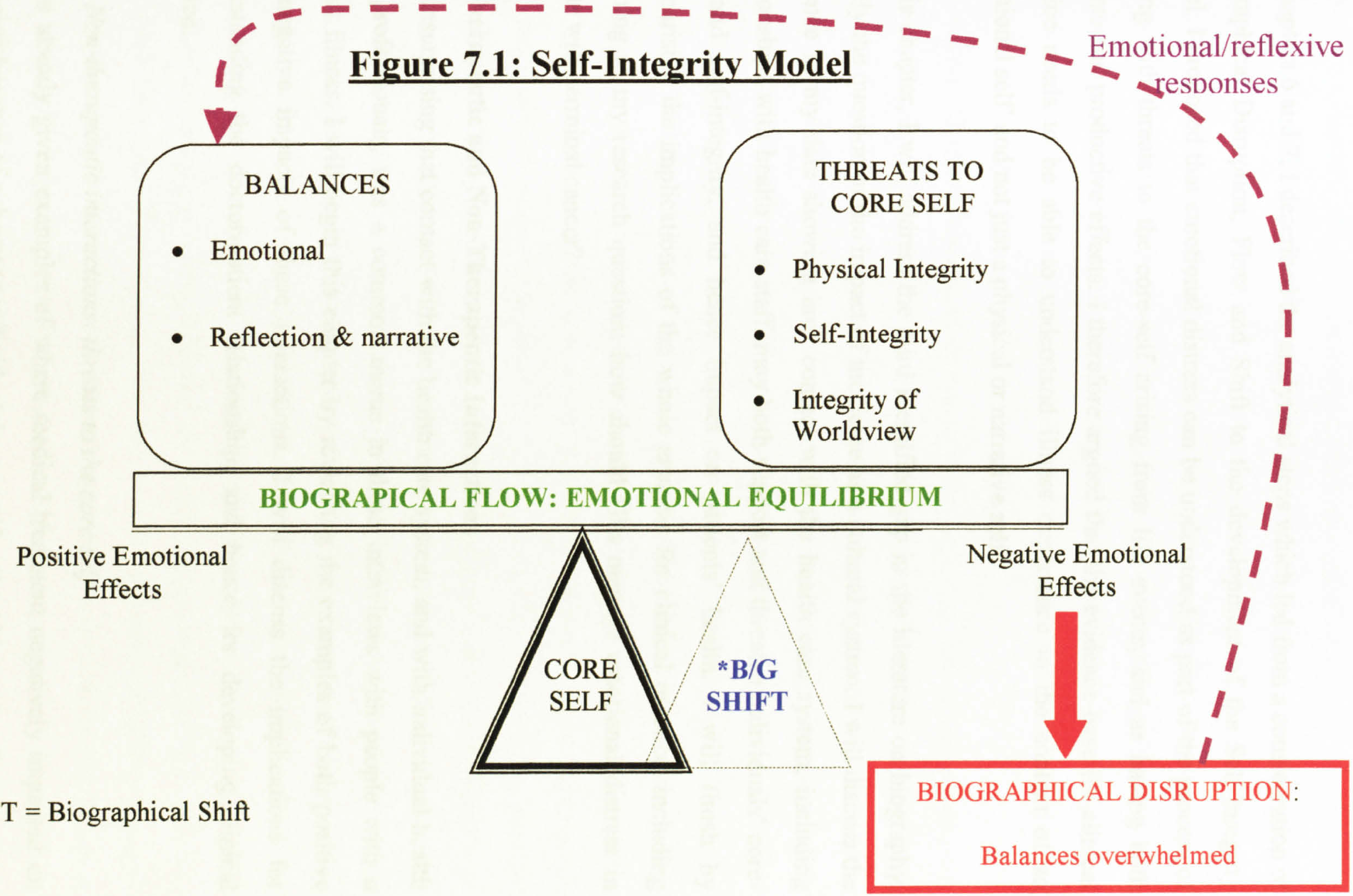
Occasionally distress became overwhelming, resulting in the Biographical Disruption described in Chapter 6. The third category identified in that chapter – so-called Biographical Shift – provides further evidence of the importance of the concept of the core-self. For the woman concerned, life events freed pre-existing constraints allowing the priorities inherent in her core-self to come to the fore. This brought emotional relief and led to a positive shift in her biographical account.

In summary, I propose a model which incorporates these themes: the model of Self-Integrity shown in Figure 7.1. Within this model, the maintenance of the core-self or Self-Integrity is the primary driver for dealing with life events.

Maintained Self-Integrity is manifest to patients as emotional stability, and to the observer as Biographical Flow. Overwhelming threats to Self-Integrity lead to an experience of marked depression for the individual, and the appearance of Biographical Disruption to the external observer. Both emotional and narrative elements are needed to support Self-Integrity, particularly for people facing threats to the core-self. The model therefore emphasises the importance of an "emotionally expressive body" (Williams 2000: 55), or embodied self, driving lived experiences; rather than focusing predominantly on a narrative self (as in Bury (1982) or Giddens (1991)).

In reviewing the literature on Biographical Disruption and Flow (Chapter 5, p79), I highlighted gaps in the evidence base and aimed to address these with my analysis. In Chapters 6 and 7, I have discussed the question of why illness is disruptive for some and not others. I have also highlighted the importance of relationships in understanding the maintenance of Self-Integrity, with both threats and comfort from interactions with others. The third identified gap was in understanding the effects of medicine as a cultural system on biography, and this will be the focus of the next chapter.

Figure 7.1: Self-Integrity Model



*B/G SHIFT = Biographical Shift

Chapter Eight: The context of medical care

In Chapters 6 and 7, I described the analytical steps which led from a consideration of Biographical Disruption, Flow and Shift to the development of the Self-Integrity model. I proposed that emotional distress can be understood as part of the process of dealing with threats to the core-self arising from life events, and as having both adverse and productive effects. I therefore argued that the evidence-base for clinical practice needs to be able to understand illness experience in the context of an 'emotional self' and not just a physical or narrative self.

In this chapter, I will address the third identified gap in the literature on biography, namely the question of the impact of medicine as a cultural system. I will discuss the evidence in my data showing how contact with the health care system, including relationships with health care staff, may both support and threaten individuals' core-self and self-integrity, and hence impact on patients' health. I will finish by summarising the implications of the whole analysis for clinical practice, including returning to my research question: how should GPs manage emotional distress in people with terminal cancer?

8.1 Therapeutic and Non-Therapeutic Interactions

It is unsurprising that contact with the health care system, and with individual health care professionals, was a common theme in these interviews with people with a serious illness. I will begin this chapter by reviewing the examples of both positive and negative impacts of these interactions. I will discuss the implications for understanding the doctor-patient relationship, and hence for developing clinical practice.

8.1.1 *Non-therapeutic interactions: threats to the core self*

I have already given examples of where medical treatment negatively impacted on wellbeing because of a threat to individuals' core-self and self-integrity. For example, Mark and Joan (in the Biographical Disruption category) described how cancer therapy threatened their physical and personal integrity through undermining their understanding of their own body, and their capacity to do what they needed to do. The exhaustion associated with treatment also limited their capacity to act to balance the threats from their illness through the narrative and emotional mechanisms described in Chapter 7. Physical and emotional exhaustion as a result of treatment thus contributed to the Biographical Disruption.

The health care system and organisation of care also constituted a threat to self-integrity for some. Having to wait for results, experiences of disorganised care, or simply of poor surroundings, threatened people's sense of self-worth, competence (being in control), and the integrity of their world view (what was right and to be expected).

> Linda: *"I think it was sort of round the time I was having the scans and waiting for results. But I think, because I said to my GP at the time, 'What if they don't, what if they won't* <u>*treat*</u> *me?...But once I'd got the final diagnosis of what was going to happen, I think the anger subsided a bit. I thought, well something's being done and I've got to play my part and get on with it. But yes,* <u>*very*</u> *angry."*
>
> Joan: *"I think it's just so scary when you're first diagnosed. For everyone. It's just a scary, scary thing. And you're depressed and you go into this cocoon, waiting for results. And then, you know, the results come and they're bad and then you go into a panic."*
>
> Helen: *"I'd just come out of hospital on the Thursday and I had to go and see [the doctor] on the Friday. And we waited oh it must have been an hour and a half. Eventually this big tall man comes out and he shouts [my name]. And I go in. And we sits down and he says, 'I'm Dr Y. Have you had the operation or are you still waiting to have the operation?' And my husband said, 'Have you not got her notes?' So he went, 'No' So he said, 'Don't you think it'd be a good idea if you went and found the notes?' So he went, 'Yes ok.' So we didn't hit it off. From that day on, we never got on because I felt as though they sent me to the wrong man. How can you interview someone that's had a big bowel operation and not have any notes?"*
>
> Joyce: *"So they put me in this ward on me own. A more depressing room I've never been in in me life. The wall across there looked as though somebody had chipped all the wall. It was* <u>*awful*</u>*. And there was the hospital outside – the cement, you know. The wall though, I couldn't believe it. It just depressed me. And when me family came in, they thought, 'My God, what's that?' I*

> *said, 'I don't know. What have they done to that wall?' You'd just think somebody had pulled something off it. It was* <u>*awful*</u>*. I couldn't get out of there quick enough. I couldn't. It was* <u>*awful*</u>*. It just. It just sent me back. It really did."*

The wait for results or lack of control over personal environment threatened self-integrity, and the resulting anxiety may also have drained people's emotional capacity to deal with other threats.

Interactions with health care professionals, usually doctors, were also identified as an important, if uncommon, source of threat to self-integrity. I have already discussed the case of Peter (Chapter 7, p116-119), whose sense of self as a fell-walker was undermined by his oncologist's dismissal. Other examples of threats were perhaps less stark, but nonetheless evident. For example, Ruth visited her GP shortly after she had been told she had metastatic disease. Although she felt she was managing well (and competence was an important part of her core-self), her GP had offered her antidepressants. This caused anxiety; the result of a discrepancy between her own and her GP's assessment of her situation and need.

> Ruth: *"Yes, [my GP] really was keen on the antidepressants. Maybe he'd had experience with people with cancer who had gone really down in the dumps and he was doing his best to sort of bring them back up to a bit of happiness. I don't know...[But] I don't know why he asked me [whether I wanted antidepressants].* JR: *Were you surprised when he asked you that?* Ruth: *Yes, I was actually. Mmm. Because I didn't think I looked depressed I may have looked worried though, possibly. Because often people say to me, 'It may never happen.' You know. But that's my normal look. And maybe that's how I looked to him. I don't know. But I was surprised at the depression and I came home a few times from there thinking, 'I'm not depressed.' And I was telling myself, you know I must look really miserable when I go. And I always made sure then that I smiled when I went in!* [laughs] *I always, as soon as I saw him I'd give him a big smile!"*

Mary did not describe a problematic consultation with her doctor. However her experiences revealed a potential threat which might arise from the mismatch between a biomedical and personal assessment of experience and need. Mary had emphasised that her core-self included being a strong woman who had successfully dealt with a life-time of difficult situations. Whilst she was managing to cope with her illness (lung cancer), she described it as a difficult and draining process. When asked how she dealt with the way she was feeling, she replied:

> Mary: *"I accept [the way I feel] and I try to find an answer for myself. And deal with it...I ask myself questions and if the answer is not what I'm looking for then it just brings on a little bit of depression doesn't it?...It's not depression. It's a quiet mode of deep thinking."*

Mary viewed depression as part of 'coping', where coping for her was a necessary part of maintaining self-integrity. However at the time of her interview, she also met the ICD-10 criteria for depression. A biomedical perspective would argue that she should be given the diagnosis and offered antidepressants (Stiefel et al. 2001). My model of Self-Integrity would suggest that any challenge to her interpretation of depression from a health care professional could constitute a threat to her self-integrity and hence wellbeing. Much depression research to date emphasises the risk of a missed diagnosis of depression (Potash 2002, Stiefel et al. 2001, Wilson et al. 2000); my work raises questions about the risks of diagnosis. The results from this study argue for caution in imposing a single biomedical interpretation of events on an individual patient's experience.

8.1.2 *Therapeutic interactions: narrative and empathy*

Although there were examples of non-therapeutic interactions in the data, people more commonly described situations in which interactions with health care professionals had been positive, and I would argue therapeutic. Effects were seen through the two mechanisms identified in 7.6 – both narrative and emotional. The identified narrative effects resonate with, and build on, the existing narrative literature (Greenhalgh & Hurwitz 1998, Launer 2002, Mattingley 1998); the emotional effects perhaps offer an extension to that literature.

Supporting reflection, restoring narrative

As previously discussed, there was no evidence that people continuously sought to construct a meaningful narrative from life-events. However when faced with threats to the core self and the resulting distress, people often described transient periods of reflection as part of their coping mechanisms. Commonly, people sought meaning based on their pre-existing assumptions and values; occasionally doctors provided an alternative source of knowledge. For example, I have already described Jenny's account of her sense of relief at being told her memory loss was due to stress and not Alzheimer's Disease (see page 145). Similarly, for both individuals experiencing Biographical Disruption, restoration of their life-narrative was supported, at least in part, by the narrative effects of the diagnostic process (see p144). Reflecting on their experiences in light of the Self-Integrity Model, I hypothesise that the improvement in their mental and emotional health came through the restoration of narrative offered by the diagnostic process, along with emotional support they received as part of that care.

Interpreting the impact of the diagnostic process from the perspective of the Self-Integrity Model also helps explain the apparent contradictions in the data. A diagnosis of depression was helpful for Joan, bringing meaning and emotional support. Yet Ruth spoke of being confused when her GP suggested she needed antidepressants. Her confusion may have arisen simply because the diagnosis was wrong. However Mary had a confirmed diagnosis of depression on the CIS-r, but her account also revealed the potential threat to her core-self if she had been offered a formal diagnosis. I propose that the data revealed the limitations of a dichotomous assessment of need based on a pathological model, namely the presence or absence of disease. Emotions, including the clustering of symptoms seen in 'depression', should be understood in the context of the lived experience of that individual – for example using the Self-Integrity model described in this thesis. The model can accommodate the pathological diagnosis, but interprets its impact (and therefore its benefit and risk) as part of the complex interaction of needs for each individual. A biomedical diagnosis is seen as only one source of information to be considered in weighing up the factors explaining an individual patient's health experiences. It offers one therapeutic path, but there may be others and alternatives may be equally, or even more, effective when considered from the perspective of Self-Integrity.

Most practising GPs will be aware of these multiple perspectives on understanding patient needs, each with relative strengths and weaknesses. However current understanding of 'best evidence' values a pathological account over others, given its origins in a scientific epistemology (Seale & Pattison 1994). This may reflect the lack of a strong theoretical framework by which to critically and judiciously use other approaches. The Self-Integrity model (including its subtle realist context) may therefore contribute to developing an alternative framework within which GPs can actively pursue a critical, reflective, but individual-centred approach to health care.

Emotional support: empathy and shared narratives

Contact with health staff brought more than just explanations for experiences. People revealed the importance of 'shared narratives': a shared experience with staff that went beyond a narrative (cognitive) construction of events to a non-cognitive (emotional) form of support. People described the emotional support from contact with health care professionals; in terms of being cared for, trust, warmth, personal care, and being made to feel special. This served to boost individual's emotional capacity to cope with the threats of their illness.

> Mary: *"It does help to talk about it with somebody like you. I'm a firm believer in talking to your doctors and counsellors...Because it, you feel so alone, with cancer."*
>
> Helen: *"It's very important to know that someone that's in there is interested in me...And Mr X - he's absolutely wonderful that man. He's brilliant. When he sees you, his face lights up. And he goes, 'I can't get over you. You look so well. You look wonderful.' "*
>
> Jenny: *"There's just something about [the hospice] that makes you feel great... They've got a nice attitude...[They're] so caring...You don't want sympathy, you want a bit of understanding. Sympathy makes you more upset and cry. But a little bit of understanding goes a long way."*
>
> Jim: *"I must say it's quite a relaxed clinic with Dr X. There seem to be two nurse practitioners...and they have established shall I say a sort of personal contact with you. And they're both experienced young ladies and they really do take care of you. It makes a world of difference, makes a world of difference."*

> Ruth: *"In the [chest hospital] I didn't find that you got any different treatment because you had cancer...You were just another body there. There wasn't that warmth there. But in [the oncology hospital] oh, the care is wonderful. The attitude of people towards you. Not sympathy or namby-pamby treatment. But just so nice. You feel like a VIP actually... And you were just so special to them. You felt you were the only one there that had cancer."*

The importance of caring was discussed in Chapter 7 (p141). I also suggested the Self-Integrity Model may contribute to developing a theoretical framework in which to adequately understand how important caring is for clinical outcomes.

Overall, data provided evidence of the importance of the clinical consultation and doctor-patient interaction in either supporting or undermining self-integrity, with implications for experiences of emotional distress. Maintaining Self-Integrity and Biographical Flow in the face of threats from life events is an exhausting process. Support from health care professionals may contribute a 'buffering effect' in providing an emotional 'boost', balancing the draining effects of threats to the core-self.

8.2 Implications for clinical practice: the clinical consultation

There is already an extensive body of literature of the consultation and doctor-patient communication. For many years, models of General Practice have emphasised the importance of the consultation and continuing relationships at the heart of good clinical practice (Chew Graham et al. 2004). Few GPs would question that the consultations cited here as examples of threats did not match up to the ideal. Most would strive to offer a caring service, albeit often constrained by the realities of day-to-day practice. So does the analysis presented in this thesis add anything new to accounts of doctor-patient communication and consultation theories?

Current models of doctor-patient communication emphasise the importance of information exchange and choice within the consultation (Burkitt Wright et al. 2004). Maguire & Pitceathly (2002) described that effective communication skills include an ability to elicit problems and concerns, give information, discuss options, and be supportive. These in turn benefit patients and doctors through supporting a more accurate identification of the problem, leading to increased patient satisfaction and concordance (ibid).

These models view doctor-patient communication as a set of skills and behaviours which can be objectively observed (Saba et al. 2006) and hence taught and learned (Salmon & Young 2005). However Saba et al. (2006) warned that, whilst communication can 'look good' if assessed by whether doctors utilise these skills, it may still not 'feel good' for the patient, or indeed the doctor. A purely skills-focused model for teaching communication skills is inadequate to support good clinical care (Burkitt Wright et al. 2004; Saba et al. 2006; Salmon & Young 2005). In a study of the experiences of women with breast cancer, Burkitt Wright et al. (2004) proposed that the outcomes from traditional training in communication skills fails to match up with patients' experiences and expectations. Patients seek a personal relationship with their doctor, emphasising the importance of trust and respect. Attitudes rather than skills inform successful consultations (ibid). However, as yet it remains unclear how to implement these recommendations within clinical training and practice.

I believe that the problematic interactions highlighted in this chapter were not simply the result of poor information exchange and problems with the communications skills described by Maguire & Pitceathly (2002), but were indicative of what May et al. (2004) described as the incongruence between biomedical and lay approaches to understanding the illness experience. The knowledge base by which each interprets situations is characterised by differing sets of principals and priorities. Peter's account was underpinned by issues I have described in my model of Self-Integrity; his doctor's by a biomedical approach focused on pathology. Differences in lay and professional knowledge are acknowledged within traditional models of communications skills (Maguire & Pitceathly 2002). Training emphasises the need for professional awareness of this in order that health care professionals can better elicit the 'true' answers from patients (ibid). However my concern arising from this study is that incongruence acts at a more fundamental level: as a potential threat to the individual patient's core-self, and hence to their well-being.

May et al. (2004) proposed that future development of successful models of primary care practice, including development of training in doctor-patient communication, must tackle the incongruence between biomedical and lay approaches to understanding illness experience. The Self-Integrity model provides a theoretical framework by which to develop understanding and clinical practice in this area through describing a patient-centred model within which to understand, research and monitor the effects of care. The model provides a framework for better understanding the therapeutic and non-therapeutic nature of doctor-patient interactions, and thus guidance for development of primary care practice. Identifying the impact of care on health outcomes is an important part of helping to develop and prioritise health care approaches. The model of Self-Integrity offers a theoretical framework within which to research and understand the patient perspective in doctor-patient interactions, and thus provides a conceptual framework within which to develop research and practice in this area.

8.3 Addressing my research question: how should GPs manage distress in people with terminal cancer?

I would argue that the model offers a number of potential benefits to a working GP, and thus to the care of patients with terminal cancer. It outlines an account of health needs grounded in patients' experiences, and thus offers a person-centred approach to understanding distress and assessing need which GPs may use to discuss distress with their patients. In addition, the respondents in my study provided a number of suggestions for dealing with distress which may be useful when talking to patients. These included behavioural approaches (doing things which give you pleasure) and making 'space' – finding time for yourself and relaxation. Whilst these ideas are not 'rocket science' (or indeed anything new to what many would consider simply 'good general practice'), the Self-Integrity model starts to build an empirical and theoretical evidence base for the importance of this aspect of care in General Practice. Thus the model offers the potential for development of interventions; including an evidence-base to support the training for, and delivery of, patient-oriented care for what might be better termed emotional (rather than mental) health problems.

Specifically, I would propose that there are two areas for development of training and practice: in the understanding and management of depression, and in the area of consultation and communication practices My study has suggested that the symptoms described in psychopathology as depression may equate to a lived experience of Biographical Disruption: the result of physical and emotional exhaustion overwhelming the support mechanisms necessary for Biographical Flow. The link between exhaustion and distress may be a useful starting point for discussions between GPs and patients, supporting a shared process of identifying need and potential action. Actions could focus on identification of existing and potential 'balances' for the individual: including behavioural approaches described by participants in this study. Antidepressants could have a role in management within the Self-Integrity model. Relief of symptoms of depression may both lessen the burden on the 'threats' side of the model, whilst also supporting greater engagement with 'balancing' processes. The model may also offer support to doctors in identifying people at risk of exhaustion and therefore depression. By focusing on patients presenting with experiences of transient distress, perhaps associated with acute life events, GPs may be able to suggest strategies to support maintenance of Flow, preventing a decline into Disruption and depression

Crucially the data also highlights the importance of the relationship with the doctor or health professional acting to support (or indeed undermine) patients' core-self, and hence experiences of emotional distress or depression. I have described the importance of developing a 'shared-narrative'. The concept refers to both a narrative account which makes sense to the individual patient and supports their core-self, but also refers to the non-narrative aspects of the relationship formed between patient and health professional – aspects of caring and respect which in turn reinforce an individual's personal-integrity and self-worth. My model suggests the need for a patient-centred model of care, with health needs identified in terms of the impact of life events on the core-self, and not simply a pathological account of need. To support such an approach, medical training would need to acknowledge different approaches to understanding illness experience as appropriate and legitimate, in order to support development of a shared narrative. This raises questions about legitimate knowledge for clinical practice – an issue I return to in Chapter 10

The work offers potential to develop a new health outcome measure based on the model of Self-Integrity for use by researchers and clinical staff. The model provides a possible theoretical framework on which to build such a tool; further development work would be needed to see if the approach is viable. A tool which could measure the relative effects of threats and balances to the core-self could aid assessment of the risk-benefit ratio of a range of interventions. Assessment of the impact of antidepressants, counselling, or even simply contact with health professionals could contribute to development of a broader (and more person-centred) evidence base on which to make "judicious" use of scientific evidence (Sackett et al. 1996: 71). Clinical uses for the tool could include providing base-line assessments of well-being, and also monitoring the effects of disease progression and treatment effects on the core-self.

The potential use of the model in supporting clinical practice forms part of the assessment of its evaluative validity (Maxwell 2002). In the next chapter, I will consider the strengths and weaknesses of the analysis against all five of the criteria described by Maxwell (ibid).

Chapter Nine: Critically reviewing the Self-Integrity model

9.1 Introduction

My qualitative analysis of the lived experiences and emotional impacts associated with living with cancer led to the development of the Self-Integrity model outlined in Chapter 7. I have proposed that this could support development of clinical practice. However it can only do so if I can demonstrate that the work is "worthy of attention" (Lincoln & Guba 1985: 290). In this chapter I will therefore critically review the strengths and weaknesses of the research by comparing it against the five quality criteria defined by Maxwell (2002) for subtle realist research (see p93). I will conclude by considering the future research needed to translate the knowledge in this thesis into clinical practice.

9.2 Reviewing trustworthiness: Descriptive validity

The primary criterion on which good qualitative research is built is that of descriptive validity: an accurate recording of what happened (Maxwell 2002). It questions whether the experiences I have described did happen: whether the respondents actually say what I have reported they said and whether my field-note observations were accurate. Ensuring the accuracy of interview data arguably relies largely on the use of good recording equipment and an accurate method of reproduction. Offering the original data for review provides a mechanism by which an external reviewer could check. However, descriptive validity also requires completeness of the record of events, albeit within boundaries which will be defined by the research question and theoretical perspective. The researcher must not only record observations accurately, but make sure that all relevant observations are captured. Thus the criteria identified to demonstrate descriptive validity included a transparent and honest account of the research process including making data available for review; a dense description of the research methods; a prolonged and varied time in the field; peer examination; stepwise replication; and a reflexive approach.

The strengths of my analysis when viewed against these criteria include the detailed and transparent account of the research process and outcomes as presented in Chapters 5-8 and in appendix A7. The latter in particular describes the reflexive, step-wise process of data collection (and analysis): detailing the sequential thought processes which guided subsequent interviews. Given the constraints of a PhD thesis, there is much additional raw data, including field notes and recordings/transcripts of interviews, which are not included in this report but are available for review. My data and analysis have also been peer-reviewed at all stages of the research though consultation with my supervisors and through the presentations listed in appendix A8.

A further strength of the study was the prolonged period of time spent in the field (two years). It allowed me time to acclimatise to a research environment and to this study in particular. Having sufficient time for reflection before and between interviews was important to allow me to move my thinking out of a clinical practice context and into one of lived experiences. Thus my prolonged field work meant that I had time to collect a comprehensive and relevant data set, including going back and collecting more data in light of the insights gained from each interview. It contributed to the breadth and depth of the detailed descriptive account of the emerging phenomena.

The potential influence of the researcher on descriptive validity has been highlighted. Inevitably, I have shaped the knowledge produced from this study, in that I have defined the question, the theoretical perspective and the methodologies that were used to generate the knowledge. The aim of the phenomenographic method was to encourage individuals to reflect on and interpret their own experiences (Marton 1986). In later interviews, I also asked people to reflect on ideas that were emerging from my analysis of previous data. However I only did this towards the end of each interview, once people had already had an opportunity to explore their own feelings.

However in my interview with Marjorie, I felt that I lost this perspective and "went native" (Lincoln & Guba 1985: 304). Marjorie's expressed experiences and concerns resonated with own thoughts of my past experiences as a cancer patient. The interview stopped being one of facilitating her reflections and became a conversation about shared experiences. The problems were further complicated by the presence of her husband. The interview became a three way conversation about shared experiences rather than a detailed exploration of Marjorie's own perspective.

The experience of this interview led to a personal questioning of how I could trust the analysis I was forming, given my own previous experiences and preconceptions. It encouraged me to re-engage in a theoretical review; and thus move from being aware that I 'should' have a theoretical basis for my work, to adopting an engaged and active search for a framework in which I could ground my research. The prolonged time in the field also meant I was able to compensate for the limitations of this interview by both learning from the experience through reflection, and collecting further data.

With this in mind, and although there were limitations in the data collection process, overall I believe the work meets Maxwell's (2002) standard of descriptive validity.

9.3 Reviewing trustworthiness: Interpretive validity

Interpretive validity describes how accurately the interpretation reflects the individual participants' perspectives: whether the data really 'mean' what I as the researcher says they do (Maxwell 2002). Establishing interpretive validity requires a critical examination of the process of interpretation. The criteria for demonstrating interpretive validity which I therefore identified in Chapter 5 were: a transparent and open account of the process of interpretation supported by evidence from the data; reflexivity; peer examination; and negative case analysis. The Hermeneutic Canons of interpretation described by Radnitsky (1968) were used to guide the interpretive process and can also be included in the 'quality indicators' for this criterion.

The strengths of the interpretive process in this study included the iterative analysis and ongoing critical reflection at each stage, including the identification and examination of negative or deviant cases. From the outset, I adopted a critical reflective process questioning the assumptions made at each stage of the research process: from the literature review and theoretical grounding of the study, to the output of the Self-Integrity model. As outlined in appendix A7, it took a number of iterations of the process and many months before I reached this stage. Deviant cases, including the identification of the new category of Biographical Shift, prompted a review of the emerging analysis, sometimes leading to a complete re-structuring of my thinking. This was a lengthy and at times exhausting process, but is offered as a strength of this research. At each stage I tested "provisional interpretations of parts...against the global meaning" (Radnitsky 1968: 27), checking how far the emerging theoretical model could explain individual narratives, or indeed themes from within those narratives. The analysis continued until I reached a point of coherence: when all the data pertinent to the research question could be explained by the emerging model (Kvale 1996, Radnitsky 1968).

However there are potential weaknesses in the interpretive process offered in this thesis. In particular there is the question of how I interpret the data from the interviews, and whether I see it as 'real' or whether it is an 'interpretation' of 'reality'. The phenomenographic method states that the researcher should accept each person's interpretation of a phenomenon as being the reality for that person at that time (Marton 1986). Analysis seeks to understand how that person has come to understand a phenomenon in that way, rather than identify what the phenomenon 'really is' (ibid). This element of Marton's description of the interview process mirrors Kvale's (1996: 3) description of an interviewer as a "miner": with the researcher seeking to uncover meaning, albeit as individually defined by the participant. The analogy of a miner suggests a fixed notion of knowledge that is there to be discovered, and also that the participant can, or does, accurately convey it to the researcher. Yet Marton (1986) also described that the researcher's role is to facilitate reflection; 'helping' the respondent to identify their own meaning. This second point instead reveals the interview as a process for generating data, but data which are shaped by both the respondent and the researcher. Kvale (1996: 4) described this alternative view of the interviewer as a "traveller", acknowledging the influence of the researcher and research process on the knowledge generated. What questions the researcher asks and how they ask them will clearly influence the data. Goffman (1959) also described the effect of the 'presented self', acknowledging that our perceptions of others will influence the way we behave and what we say.

The impact of particular people's perceptions of me as the researcher on their responses was evident within the data. For example, Jim referred to me throughout the interview as "*doctor*". The responses he would have given to a researcher who was not a doctor may have differed. Mary, on the other hand, started by calling me Joanne (as I invited all participants to do), but then in the course of the interview revealed her identification of me in a number of different roles. Near the start of the interview, she told me about her own background in nursing. This arguably reflected her awareness of my clinical role, and hence a desire to establish her own health care credentials:

> Mary: *"I've nursed a lot all of my life. I've worked with Down's syndrome, learning disabilities, all sorts of patients in you know medical and surgical. Since I was sixteen."*

She was also keen that I shouldn't see her as ill, again perhaps reflecting her awareness that I am a GP and may see things in a certain light. Having described that she experienced transient periods of feeling down, she qualified it by saying:

> Mary: *"But I've never been treated for depression in my life at all. I don't think I am depressed in the medical terms."*

However only a few sentences later, she stopped alluding to me as a doctor and said, *"But I'm not worried about a thing* *sweetheart.*[my emphasis]*"* A short while after that, she referred to me once again as a doctor, but this time as therefore somebody who was 'easier to talk to':

> Mary: *"Your doctor's important to talk to isn't she? I would never in a million years sit down and speak to my family like this, the way I'm speaking to you. It's a cheat really. Because I'd sooner speak to a stranger than my own. Because my own are involved; you're not involved."*

And only a few minutes later when I asked her about whether she would be happy to talk to her doctor about how she was feeling, she replied:

> Mary: *"No, can't stand doctors. Can't talk to them. I mean I can talk to you as a lady doctor - female. Woman to woman basis. I'm not talking to you as a doctor now, I'm talking to you as a friend. You know, that's the way I look at you."*

Mary's account offers insights into the different ways she viewed me throughout the interview, with suggestions that her perceptions may have shaped some of her account. Her example highlights that respondents' accounts need to be seen as a response to a reflective process in which I have had an influence. Another researcher undertaking this study may have collected a different data set. I believe that as we would both be looking in on the same phenomenon, there would be similarities in the data; the differences would reflect our different perspectives. However assuming both analyses met Maxwell's quality criteria (2002), both would potentially be equally valid. The use of one knowledge set over the other would depend on the purpose for which the knowledge was being used. My analysis sought to identify differences between people's reported perceptions which might offer insights into development of clinical care. I was looking to build a theoretical or interpretive account, not to describe a 'reality'. In particular, I hoped that the knowledge in my theoretical account offered utility in treating emotional distress. Utility is the final criterion for trustworthiness proposed by Maxwell (2002) and is discussed at the end of this chapter.

9.4 Establishing trustworthiness: theoretical validity

Theoretical validity looks at how well the analysis works as an interpretation and explanation of the phenomenon, and requires consideration of whether the research/knowledge is grounded in existing theory, and demonstrates reflexivity, structural coherence and referential adequacy through an iterative approach (Lincoln & Guba 1985, Maxwell 2002).

Strengths of my analysis therefore lie in the iterative and reflexive process of analysis and interpretation already described. Emerging findings were tested on, and hence modified by, new data - providing the "referential adequacy" referred to by Lincoln & Guba (1985: 313). Structural coherence is demonstrated in the presentation of this thesis and the model presented in figure 7.1. A further strength of the work lies in the extent to which it is grounded in the existing literature. My analysis supports and builds on the existing biographical literature, and also theoretical work on the self and emotions.

The Self-Integrity model emphasises the impact of illness of the self. It highlights the importance of narrative and emotions in understanding the impact of illness, and also in offering therapeutic options. The ideas build on the work of both Bury (1982) and Giddens (1991). They focused on a narrative self, arguing that continuity of narrative and meaning brings emotional stability; disruption leads to anxiety. This approach supports psychological accounts which see emotions as the 'product' of cognitive processes: for example, depression is caused by disordered thoughts (Beck 1976). Within primary care, there is a growing body of literature emphasising the importance of narrative (Greenhalgh & Hurwitz 1998, Launer 2002) and meaning (Dowrick 2004), which provide suggestions for development of clinical and research agendas. My analysis provides evidence in support of these approaches: for example the importance of diagnosis in offering meaning (as described on p144); also evidence that transient periods of reflection were responsible for causing distress but also helping people to feel better (see sections 7.5.2, p137 and 7.6.2, p143).

However, I also identified that a narrative focus alone was not adequate to explain the accounts of lived experiences of my participants. People often spoke about how they were feeling; a search for meaning was not a common theme in any of the interviews. People described how their emotional state determined what they did and, for some, what they were thinking (see p138). My participants described a range of effective approaches for dealing with distress which focused on the emotions: including activities to promote positive emotions, caring and being with others, and physical effects from touch and complementary therapies. My data highlighted the importance of emotional aspects of experience - that which is *felt* rather than spoken. My Self-Integrity model emphasises the importance of the emotional self in mediating experiences of threats from life events.

Thus the Self-Integrity model complements the narrative-based medicine approach described by Greenhalgh & Hurwitz (1998) and Launer (2002), since both acknowledge the value of narrative as a tool to understand human illness experience. The therapeutic potential of narrative is also central to the two models, recognising the maintenance, restoration or reconstruction of narratives in supporting well-being. The importance of the role of health professionals in that process is also emphasised. However narrative medicine assumes a narrative model of the self, and self-identity; whilst my model proposes a need to focus on an emotional self. Emotions or feelings were identified as the mechanism by which people experienced threats to their core-self, and which drove actions and responses. Although reflection and seeking meaning were transient responses to events for some people, there was no evidence that people's sense of self depended on maintaining a narrative account of themselves. The central role for the 'self' in understanding experiences and distress, combined with the absence of an emphasis on a narrative self, were evident from the earliest stages of analysis of my data (see appendix A7). These observations supported my decision to continue with the phenomenographic approach described in Chapter 5, rather than switching to a narrative medicine methodology.

However, I started the research with an interest in understanding emotional experiences, influenced by my work as a GP where people often come to see me because they 'don't feel right' rather than because they 'can't work something out'. The information leaflet sent to participants influenced the study as being interested in people's feelings (see appendix A3); my interview schedule started with the question 'how are you feeling at the moment' (appendix A6). In addition, I defined the core-self as what matters to people; but defined what matters, in part, as dictated by people's emotional experiences. This raises the question as to whether my emphasis on an emotional self was an artefact of the research process and my influence as a researcher, rather than a 'true' experience.

Other authors have also questioned whether a cognitive or narrative account of the self can be adequate, notably the work of Sabat & Harré (1992) and Sabat et al (1999) focusing on people with dementia. The authors queried the implications of a narrative understanding of the self for people with dementia, where a loss of cognitive function (and therefore narrative) could imply a 'loss of self'. Charmaz (2002) critically reviews the use (and over-reliance) of narrative in understanding chronic illness, arguing that we need to focus not just on the words people use, but also on the 'silences' and what is not said. Embodiment theorists point to the need to look not at just how people conceptualise experiences, but how people 'feel' experiences. For example, Williams & Bendelow's (1998: 138) account of the embodied self identified a description of emotions which perhaps describes the essence of the emotional self revealed within my data:

> *"Emotions are most fruitfully seen as embodied existential modes of being - ones that centrally involve self-feelings as the inner core of human emotionality and an active engagement with the world."*

Thus there is theoretical support for my proposal of an emotional self, but with room for further research (see 9.6.2)

9.4.1 *Resonance and dissonance with existing models of cancer experiences*

I started Chapter 5 with a consideration of other theoretical approaches to understanding illness experience, including those of dignity (Chochinov et al. 2002a), spirituality (McClain et al. 2003), and resilience (Nakashima & Canda 2005). However, I was concerned that by focusing on a single aspect of illness experience, my study may not adequately support development of care of the complex needs of an individual. I turn now to review my model of Self-Integrity in light of these existing models to explore whether my approach did indeed offer new insights.

Chochinov et al.'s (2002a) study of dignity identified threats to, and supports of, dignity, including: illness-related issues (level of independence, and symptom distress); together with social concerns and relationships (privacy, social support, concerns about being a burden whilst ill, or of leaving others behind). Also described are processes for maintaining dignity, including: supportive perspectives (characteristics and attributes such as continuity of self, reliance, and acceptance), and supportive practices (seeking spiritual comfort, and maintaining normalcy). In a separate study, the research team demonstrated that loss of dignity was associated with distress (2002b).

Both my model and Chochinov et al.'s (2002a) account of dignity attempt to describe a dynamic process of seeking to deal with threat and associated distress. Themes such as continuity of the self, the importance of relationships, and continuing to maintain routine, normal behaviour are seen in both accounts. Defining what dignity actually is remains problematic; although I have also discussed the limitations of my own attempt to define the central concept in my model, that of the core-self. Perhaps the most significant point of divergence is in the applicability of the two models. Dignity is an important moral concept underpinning health care approaches (Tad et al. 2002), but it is less clear how the concept would apply to understanding, for example, Helen's distress in light of her husband's suicide. My Self-Integrity model also provides specific examples of how changes to clinical care approaches could support patient experiences and outcomes; Chochinov et al. (ibid) have not yet described a model of care. Both models need further development; although each may offer insights into the other.

A protective effect of spiritual well-being on end-of-life despair, or distress, was demonstrated in the work of McClain et al. (2003). The importance of a sense of meaning, and of faith (both as a set of beliefs, and practices) was also seen within my data set. However McClain et al. (2003) acknowledged that it remains unclear whether interventions exist which can boost an individual's spiritual well-being. This point highlights two distinct issues: firstly a lack of clarity in describing how to address spiritual needs, and secondly a lack of evidence that any such approaches can make a difference. Attempts have been made to describe conceptual frameworks for providing spiritual care (for example, see Ross 1994). However such models often refer to, but do not adequately define, what 'spiritual needs' are; reflecting the diversity in definitions of spirituality (Taylor 1998). Where definitions are offered, they include ideas such as 'meaning' and 'value', subjective concepts which are not easily 'measured' and therefore evaluated (Whipp 1998).

My Self-Integrity model also refers to subjective ideas such as 'what matters' to an individual. However my explicit intention was to develop a model which offered insights into clinical care. The analysis identified specific recommendations for clinical practice (see p159) which may be subjected to further empirical study. Therefore whilst I recognise there is overlap between ideas described in the spirituality literature and my work, currently I believe that the Self-Integrity model offers greater potential for development of primary care practice.

Research into the concept of resiliency again emphasises a dynamic process of maintaining and recovering health; and includes references to physical, psychological, social and spiritual aspects of people's lives and experiences. However a conceptual model of the process in terminal illness has only recently been described (see Nakashima et al. 2005). The model emphasises the interaction of the individual with their environment and social setting, and includes references to meaning and spiritual needs. The latter is offered as strength over an earlier model of resilience (Bergeman & Wallace 1999), which focused on functional outcomes over personal well-being. Yet the spiritual focus in Nakashima et al's model (ibid) is also its weakness, since the concepts are poorly defined. Once again, although the findings in their study resonate with mine, there are few specific recommendations for development of clinical practice, identifying how resilience may be supported and developed in individual patients.

Finally, the analysis identified in this thesis was noted to resonate with recent developments in the concept of posttraumatic growth (Tedeschi & Calhoun 1995). This describes a process whereby significant life events lead to reflection and re-evaluation of personal priorities and future goals, leading to positive life changes. My data also demonstrated that a cancer diagnosis, although stressful, does not have to be an entirely negative event. Indeed several people described positive effects from having lived through the experiences; most notable in the Biographical Shift described by Angela. Similar ideas are described in the work of Siegel & Schrimshaw (2000) in women with HIV/AIDS, as well as in studies of breast cancer patients (for example, see Cordova et al. 2001, Manne et al. 2004). However ideas of personal growth emphasise cognitive approaches of reflection and re-evaluation. The importance of emotional drivers, as identified within my thesis, is overlooked in a model which emphasises psychological impacts and "cognitive processing" (Cordova et al. 2001: 182). In addition, the posttraumatic growth literature focuses on major life events which might be readily understood to be potentially 'traumatic'. However, my analysis also described smaller, daily events which were also potential threats to the core-self and contributed to the potentially exhausting experience of maintaining Biographical Flow. For example, the noxious effects of a non-therapeutic interaction between Peter and his doctor had a significant impact on his well-being, although may not be recognised as a 'traumatic event' within the model of posttraumatic growth. Thus whilst there is certainly overlap between the two models, I believe that the Self-Integrity model offers greater insight into 'routine' experiences of stressors and distress, and may therefore be more supportive of development of primary care practice.

I believe the Self-Integrity model described in this thesis is supported by, and in turn develops, the existing theoretical and empirical literature. The emphasis on the emotional self in my work will have been influenced by my research approach; however this is based on a transparent and reflexive account supported by peer-reviewed theoretical accounts within the literature. I believe the research is grounded in, and develops existing theoretical accounts of the self and experience. This theoretical validity of the work is significant in considering the extent to which the results can be applied elsewhere, namely its generalisability.

9.5 Establishing trustworthiness: generalisability

Generalisability refers to the ability to draw inferences about other populations from the results of a research study. The criterion described by Maxwell (2002) required that the researcher provide sufficient information so the reader can decide if the results can be used in another setting. This includes providing sufficient details of the sample, which can then be compared to wider demographic data.

From the perspective of the quantitative methods used in the prevalence study in the first half of this thesis, a weakness of this study lies in its small sample size. In addition, although levels of distress were high (as evidenced by scores on the Edinburgh Depression Scale), only two people met criteria for ICD depression and only one was interviewed. There was therefore limited capacity to explore the experiences of depression as it would be understood in medical terms. It would have been interesting to have identified more patients with depression as defined by pathological models from ICD-10 or DSM-IV so as to have a bigger dataset by which to directly compare biomedical and lay accounts of depression (rather than distress). The study also only provided a snap shot of experience, however detailed, perhaps limiting the extent to which the results can be understood in the context of a continuing therapeutic relationship between a GP and patient.

However from the perspective of a qualitative study, the strength of my study lies not in the numbers, but in the explicit descriptions of the selection of the 19 participants. The sample was chosen to include people with features felt to be important to understanding the phenomenon. Sampling processes were also adapted in light of the emerging analysis to ensure it allowed adequate exploration of theoretical ideas. The sampling strategy together with the theoretical grounding of the study discussed in the previous sections support the argument that the results of the study may be generalised on theoretical grounds. In other words the concepts arising from the work, including the Self-Integrity model, may be able to explain emotional distress in other people with terminal cancer.

In Chapter 2, I proposed that terminal illness can be viewed as a critical situation; offering insights into the everyday world through a detailed examination of an extreme example (Giddens 1979). My analysis revealed that life events other than the cancer were responsible for the disruptive effects described. The Self-Integrity model may therefore also offer insights into distress associated with other life events and be of use more generally by GPs in everyday practice outside of palliative care.

On the basis of the theoretical and empirical issues outlined in this section, I would argue that the findings from this study may be generalisable to other people with terminal cancer, and even people experiencing distress associated with other life events. However this would need testing empirically through further research.

9.6 Establishing trustworthiness: evaluative validity

I have sought to demonstrate that the process of knowledge production in this research project has met standards of honesty and transparency, is grounded in both the empirical data and existing theoretical concepts, and thus meets Maxwell's criteria for trustworthiness (2002). The final criterion is also the one which will be of most concern to practising GPs: namely the requirement to demonstrate evaluative validity, or utility. Evaluative validity asks the question 'so what?' How can the knowledge from this research study be used to help us live in the world, and inform health care? Maxwell (ibid) argued that an explicit consideration of utility was a crucial part in judging the 'quality' of knowledge. In Chapter 8, I discussed the potential utility of the findings in informing clinical practice. However, ultimately whether the Self-Integrity model can inform and contribute to clinical practice may be something which is determined retrospectively: through further developmental work and its application in a clinical setting.

9.6.1 *Establishing utility through future research – developing clinical practice*

I have deliberately not undertaken a process of member checking within this study for the reasons outlined in Chapter 5. However, presenting this model to either patients (or potential patients) and doctors to assess its resonance for their own lived experiences may help refine both the description of the model and development of its utility.

Further empirical exploration of the Self-Integrity model is also needed to explore its relevance in explaining lived experiences, including the impact of health care. The critical review in this chapter has highlighted the lack of people with severe or current depression in my study sample. This suggests a need to repeat the study, exploring the utility of the model in a sample of people with more sustained or severe depression, including those currently receiving antidepressant therapies. This work might also provide some insights into the questions of risks and benefits of a diagnosis of depression as identified in Chapter 4. Future research studies may need to consider alternative sampling strategies: perhaps sampling from a wider geographical area, or focusing the study in a palliative care population with a more concentrated collection of patients meeting pathological criteria for depression.

The model suggests that maintaining continuity of the core-self (at least in terms of Biographical Flow) in the face of life events is in itself an exhausting process. This theory needs further exploration both within and outside the setting of terminal illness. Given that biography was identified as a dynamic effect, I would also propose the need for longitudinal studies to assess how well the Self-Integrity model explains ongoing lived experiences. I have proposed that whilst illness causes disruption, disruption may also cause illness. The model may therefore offer some insights into other illnesses which are sub-optimally defined within a pathological framework (for example Chronic Fatigue, stress, and the phenomenon of 'medically unexplained symptoms') and this warrants further investigation.

I would seek to refine understanding of interventions which support emotional wellbeing, including an assessment of the relative impact of emotional versus cognitive or narrative-based interventions in supporting the well-being associated with self-integrity. This could ultimately lead to some form of trial of a clinical intervention. The Self-Integrity Model may also provide a theoretical framework in which to develop understanding of interventions which are already being piloted. For example, Harris et al.'s (1999) work on befriending emphasises the importance of relationships in improving the health of those with mental illness. England & Lester (2006) have identified that relationships are a key factor in predicting successful outcomes in the work of Graduate Mental Health workers.

Ultimately if the Self-Integrity model proved to be useful and relevant to stakeholders, I would propose work to undertake a more detailed descriptive analysis of each of the component parts in order to support development of a 'self-integrity outcome measure'. This could be used to test the effect of interventions (including consultations) and hence guide development of practice and training.

9.6.2 *Establishing utility through future research – developing theories of the self*

Theoretical models of the self underpinning the biographical work of Bury (1982) and others, along with narrative approaches described by Greenhalgh & Hurwitz (1998), Launer (2002), and Mattingley (1998), assume self-identity relies on an ability to maintain a continuous narrative of the self. Giddens (1991) proposed that this narrative self consists of three elements. At the centre is an inner core-self; presumed to be cognitive in nature, and the product of psychological development processes which start in childhood. This inner core offers "ontological security" (ibid: 31) – a combination of both meaning (cognitive support) and trust (emotional support) – which provides the basis by which we may interact with the outside world. The next 'layer' is the narrative-self of which we are consciously aware and which seeks to maintain a continuous narrative, and thus a "protective cocoon" (ibid: 40), in the face of interactions with the outside world. The idea of an outer 'presented self' resonates with the work of Goffman (1959), describing the impact of external influences on the nature of the 'self' which is revealed to that external world. Giddens' (ibid) account reflects his origins in psychology theory, emphasising a cognitive model of the self with emotions viewed as the product of psychological processes.

The Self-Integrity model proposed in this thesis also suggests an inner self, but one that is primarily known to the individual through emotional experiences rather than narrative processes. The concept of a 'core-self' is supported by the observed distress when these elements were threatened. The stability of these central elements of the self was discussed in section 7.6.4 (p144). Other authors have also questioned whether a cognitive or narrative account of the self can be adequate, notably the work of Sabat & Harré (1992) and Sabat et al (1999) focusing on people with dementia. The authors queried the implications of a narrative understanding of the self for people with dementia, where a loss of cognitive function (and therefore narrative) could imply a 'loss of self'. Charmaz (2002) critically reviews the use (and over-reliance) of narrative in understanding chronic illness, arguing that we need to focus not just on the words people use, but also on the 'silences' and what is not said. Embodiment theorists point to the need to look not at just how people conceptualise experiences, but how people 'feel' experiences. For example, Williams & Bendelow's (1998: 138) account of the embodied self identified a description of emotions which perhaps describes the essence of the emotional self revealed within my data:

> *"Emotions are most fruitfully seen as embodied existential modes of being - ones that centrally involve self-feelings as the inner core of human emotionality and an active engagement with the world."*

There is both theoretical and empirical support for a model of the self placing emotions at the core. However both approaches highlight the difficulties in seeking to clarify the nature of the core-self. I have argued that an individual experiences the core-self through emotional effects: distress in the face of threats, well-being when supported. As an external observer it may also be possible to 'access' these emotional effects, albeit indirectly, for example through interpretation of body language and other non-verbal communication. More commonly, access to the 'inner-self' comes through cognitive approaches, be that through internal self-reflection or an externally delivered narrative. Constructing a narrative to describe or explain an emotional experience inevitably involves interpretation, and will be influenced by the knowledge and expectations of the interpreter. In a research setting, there will be at least two elements of interpretation: that of the individual whose 'self' is under study, and that of the interviewer/researcher. Empirical research into the 'nature of the core-self' is thus fraught with difficulties of interpretation.

My thesis never sought to establish the 'true' nature of the 'core-self', not least since the subtle realist perspective adopted by the study rejects a search for 'truth' as the central purpose of knowledge construction. However future research looking at the utility of a theoretical model of the core-self emphasising emotions would potentially be of use in supporting a greater emphasis on emotions and emotional approaches in health and health care. Anthropological studies involving extended periods of contact with individuals allowing time to observe both their emotional experiences (verbally and non-verbally), and understand the conceptual models which may influence individuals' interpretation and expression of those experiences could be of benefit.

9.7 Conclusion

Although this study was limited, in that most people interviewed were physically and emotionally relatively well, I believe it meets Maxwell's criteria for trustworthiness through providing an honest, coherent and transparent account of the collection and analysis of data from 19 people with advanced metastatic cancer. From the positivist stance advocated in Sackett et al.'s (1996) emphasis on 'scientific knowledge', the weaknesses of this study lie in its interpretive stance and the influence of me as a researcher on the process. However I would argue these are tempered by the transparent account of the reflective processes of interpretation leading to construction of the emerging 'knowledge' within a subtle realist framework. The study met standards for descriptive, interpretive and theoretical validity. It is grounded in a strong theoretical framework, both in terms of the research methodology and the topic area. It both resonates with and builds on the existing theoretical and empirical literature; and addresses some of the inconsistencies.

It proposes a new model for understanding patient experiences which may be useful in primary care clinical practice. As well as being grounded in the empirical data and theoretical ideas outlined above, the model also resonates with existing clinical practice. Primary care has always emphasised the importance of ideas such as personal care, holistic and patient-centred care, and continuity of care. However the formal evidence base to support these approaches is still scanty; but necessary to ensure these aspects of care are preserved and prioritised within health policy and practice. The model therefore has the potential to support development of both research and clinical practice.

In this thesis I have therefore presented two studies examining the question of emotional distress in terminally ill patients from different theoretical perspectives. I have discussed the strengths and weaknesses of each, including their individual implications for clinical practice and research. In the final chapter I shall review the entirety of the thesis and thus summarise the implications for understanding knowledge in clinical practice.

Chapter Ten: Knowledge and clinical practice – new insights

10.1 Introduction

In this thesis, I set out to critically explore the nature of knowledge and evidence in order to develop understanding of its use in clinical practice. I examined two different types of knowledge available to understand the problem of emotional distress in people with terminal cancer. These were a biomedical pathological account focusing on depression, and a patient-centred experiential account looking at narratives and the self. The aim was to develop breadth and depth of understanding of the topic, but ultimately to comment on knowledge and practice. I begin this final chapter with a summary of the thesis as a whole before considering the implications for understanding knowledge in clinical practice.

10.2 Summary

In Chapters 3 and 4, I explored the efficacy of a biomedical, pathological model in understanding distress, focusing on depression. I described a depression prevalence survey of terminally ill cancer patients in primary care. 4.1% of the sample was identified as suffering from a cluster of symptoms which differentiated them from the rest of the sample, and which is presumed within biomedical theory to result from a pathological state of depression. Knowledge derived from previous research would suggest that these people may benefit from pharmacological intervention to improve their depression, and hence quality of life and wellbeing (Stiefel et al. 2001).

The identified prevalence was lower than expected based on previous palliative care research. Research tools for measuring depression were also found to function differently in this population. The results highlighted the need for a critical review of the adequacy of the current depression knowledge base for informing primary care practice. A critical review of the literature on depression in patients with terminal cancer was described in Chapter 4. This raised ontological and epistemological uncertainties with regard to current pathological conceptions of depression, further questioning the limitations of the knowledge base for informing practice.

Overall the review highlighted the need for primary care specific research into distress in people with terminal illness. I questioned whether the current pathological model of depression should be considered a 'better' source of knowledge to inform practice simply by virtue of being derived from a biomedical, scientific account of illness and disease. I argued the need for further research into the utility of pathological accounts of depression in managing distress in a primary care setting. I proposed the development of longitudinal studies to identify the interaction between depression symptoms and other prognostic indicators in determining outcomes, focusing on wellbeing rather than depression status (given the described uncertainties). I raised questions about the validity (or truth) of a pathological model of depression, at least as currently conceptualised, but also acknowledged work that has demonstrated improved outcomes with antidepressants. I therefore suggested a need to research and identify the balance of risks and benefits of a 'diagnosis of depression'.

In Chapters 5-8, I presented a qualitative study which sought to describe a patient-centred account of the emotional experiences of living with terminal cancer. I identified that emotional distress arose from threats to what I defined as the core-self - things which mattered most to people. Transient distress was common, but could be accommodated by a combination of narrative and emotional supportive mechanisms. In a minority of people, these mechanisms were overwhelmed by a combination of physical and emotional exhaustion. The result was disruption of an individual's life-narrative together with a profound emotional disturbance, the latter being clinically diagnosed as depression in both cases. The results highlighted the importance of understanding illness in the context of an embodied emotionally expressive self, and not simply a physical or even narrative self.

In Chapter 9, I critically reviewed the knowledge derived from this qualitative study. In particular I focused on the knowledge production process (Doucet & Mauthner 2002), seeking to demonstrate that the work met standards of descriptive, interpretive, and theoretical validity. I discussed the question of generalisability identifying theoretical grounds why the ideas arising from this study may be more widely applicable, but acknowledging the inherent uncertainty. I proposed that the work has implications for clinical practice and future research. The utility of the knowledge therefore may be hypothesised but ultimately will only be determined in retrospect.

10.3 Breadth, depth or confusion?

Working clinicians already know that patients have their own explanations and experiences of health and illness, and that these will often differ in some way from a clinical account. In this thesis, I have used patient experiences to develop a knowledge base which meets the quality standards described by Maxwell (2002) and thus suggested that it offers insights into the development of clinical practice. But does my work really add depth of understanding to patient care by offering an integrated appreciation of the multidimensional nature of the experiences? Or have I simply added breadth: a critical awareness of different perspectives, but with limited applicability into everyday clinical care? Have I managed to develop a useable knowledge base which moves beyond a pathological model of disease, or have I simply confused the picture by adding in more 'data' with limited sense of how a clinician can implement that knowledge?

In reviewing the work in this thesis, I would propose that the two knowledge bases are not incompatible, and indeed may be seen as complementary and synergistic if viewed from a subtle realist perspective. Both offer insights into patient experience, each with its strengths and weaknesses; I am not saying that one is better or more valid than the other. The Self-Integrity Model proposed in Chapter 7 argued that 'mild' or at least transient depressed feelings resulted from threats to the self. More debilitating depressive illness was the result of exhaustion and the lived experiences of Biographical Disruption. The pathological model described within biomedicine, which assumes an organic problem in the brain requiring pharmacological intervention, could be a common pathway through which the effects of threats are manifest. Pharmacology may therefore potentially offer some support through lessening the negative emotional effects of threats; supporting the left hand side of the model in figure 7.1 (p148). The qualitative study underlines the call made in Chapter 4 for research into the utility of a pathological concept of depression in understanding need; using patient-centred (rather than disease-centred) outcomes, and exploring the benefits as well as the risks to the self (and maybe Self-Integrity) from a diagnosis of depression. Thus the two bodies of work are potentially complementary.

However the two bodies of knowledge do not directly map onto each other. For example, in Chapter 5 I suggested that the symptom cluster described by biomedical theory as depression might equate to a lived experience of Biographical Disruption. One woman in the Biographical Flow category met the ICD-10 criteria for depression at the time of interview. This raises questions about the limitations of both bodies of knowledge and highlights the need for further exploration of each. Awareness of both and comparison between the two has the potential to offer new insights. For example, if depression is the lived experience of Biographical Disruption (for some at least), this offers potential for development of new interventions. The prevalence survey work highlighted the need to assess the positive *and negative* impacts of a diagnosis of depression. An outcome measure based on the Self-Integrity model could support this work. Thus the patient-centred context of the model of Self-Integrity offers an additional approach to understanding the benefits and risks of a diagnosis of depression, as well as identifying alternative approaches for conceptualising and dealing with distress.

However integration of the two is only possible if we remove the question of 'truth' as the 'gold standard' for knowledge production with its resulting limitations on epistemological approaches. Within the subtle realist stance of this thesis, I was able to focus on the method of knowledge production and the utility of the knowledge in assessing the 'quality' of that knowledge. This approach offers a way to broaden the knowledge base available for clinical practice but without loss of critical integrity. Thus combining the knowledge offered from both studies leads to a patient-centred model of understanding distress which uses both knowledge forms, but prejudices neither on the basis of an ontological perspective.

10.4 Knowledge and practice

This thesis has raised important issues about the nature of knowledge in clinical practice. I have argued that we need to be able to integrate different knowledge types in order to adequately explain and address the multi-dimensional experiences that are patients' health needs. However I do not disagree with Sackett et al.'s (1996: 71) call for practice based on the "judicious use" of knowledge. I believe that the knowledge framework for clinical practice must explicitly include the range of knowledge available from different epistemological perspectives. Training of health care professionals must enable them to knowingly critique and employ that range of evidence to support the needs of their patients. This thesis highlights a need to better understand the "judicious" aspects of evidence-based practice (Sackett et al. 1996: 71) through reflexive awareness of the utility and weaknesses of different forms of knowledge. As previously stated, "understanding the nature and credibility of knowledge and evidence is the first part of the application of evidence to practice" (Jones & Higgs 2000: 313).

A broadening of what is viewed as a legitimate epistemological stance may better support the role of the health professional in providing access to a wider knowledge base; and indeed my thesis has also suggested it may have a direct impact on health outcomes for patients. In Chapter 8, I discussed the problem of the incongruity between biomedical and lay approaches to understanding illness experience (May et al. 2004) which may have contributed to Peter's experiences of distress in a consultation with his oncologist (p118) through the potential to threaten an individual patient's core-self and well-being.

Hofer & Pintrich (1997: 117) define "personal epistemology" as the individual's personal theories or beliefs about "the nature of knowledge and processes of knowing". This personal epistemology may be important in determining the nature of a clinical relationship through its influence on the doctor's ability to comfortably work with the range of knowledges needed to support the Self-Integrity of another. I would hypothesise that a flexible epistemological approach in a GP would be more likely to promote congruence with patients, and thus to support maintenance of Self-Integrity. Whilst from the perspective of this study, this would be desirable in all consultations it may be particularly important (and of 'therapeutic benefit') in people experiencing distress related to threats to the core-self. Current research into personal epistemology within medicine has tended to focus on understanding how students and doctors develop scientific ways of knowing (Knight & Mattick 2006). My study suggests we need to understand more about how doctors use other forms of knowledge in practice, including their professional and experiential knowledge but also the folk models of health acquired outside of the medical context (Helman 2001).

I believe that many doctors are already aware of the different perspectives on experiences which patients bring to the consultation. However, I also believe that doctors need a framework by which they can make "judicious use" (Sackett et al. 1996: 71) of all the knowledge available to them. Shorter (1991) argued that there has been a shift in emphasis in clinical care to 'cure' over 'care'. This has meant a focus on organic illness; but with medical practice is less able to deal with the lived experiences of multiple symptom complexes presented by patients (ibid). By providing a theoretical framework in which these issues are made explicit, the Self-Integrity Model may be able to contribute to development of clinical care which can fill this gap.

Yet Salmon & Young (2005) warned that patients place less value on their doctor's concern over emotional factors and social context than experts might think. Patients may not want or expect psychosocial elements in the consultation; and they may be seen as intrusive, inappropriate and hence detrimental to the clinical relationship. Proposing a model which advocates addressing the concerns of an 'emotional self' may have adverse effects. I question whether this raises issues about the importance of the patients' personal epistemology as well? Medical knowledge and scientific perspectives are not wholly contained within professional circles. Many patients may view health experiences, or at least those they bring to their doctor's surgery, in a pathological framework. Some may not want to discuss the possibility that depressed feelings may reflect wider, personal issues rather than simply requiring the doctor to give them a course of medicine to treat the pathology. The personal epistemology of patients may therefore also be important, with implications for health promotion and health education. Perhaps personal epistemology is an explanatory factor in predicting whether people experience Biographical Flow or Disruption?

I would therefore argue that we should view both the biomedical account and the Self-Integrity account simply as models: theoretically and empirically grounded attempts to explain human experience. The knowledge described in these models may (and should) be judged, but against a broader quality framework (for example that described by Maxwell) rather than an appeal to 'truth' based on a single epistemological perspective. Similar criteria may be applied to other theoretical tools found within the literature, for example accounts of dignity and spirituality as discussed in Chapter 5. The clinician's role should arguably be to have a 'tool bag' of such models with a critical understanding of the strengths and weaknesses of each. He or she may then draw upon whichever are most appropriate to support the individualised care of the patient sat in front of them.

An exploratory study of how GPs use knowledge in practice, including the discrepancies between the ideals of evidence-based medicine and the reality of clinical practice, may be useful to develop thinking in this area. Better understanding of the structures GPs use to integrate knowledge could help inform development of training and educational practices. Investigation of personal epistemology may offer some insights into therapeutic interactions and the ability of a health care professional to engage with a patient, including a measure of their ability to deal with complex problems. Viewed from the perspective of a Self-Integrity model, clinical practice must be able to accommodate the individual knowledge of the patient being treated, or risk contributing further to the threat to the individual's core-self already raised by the illness. However I would also argue that we also need to explore the impact of the personal epistemologies of patients in determining health status and outcomes. Longitudinal qualitative studies following up patients with chronic health problems could provide a starting point for exploring these ideas.

10.5 Strengths and limitations of the thesis

I have already described the strengths and limitations of the individual studies described in earlier chapters. Here I turn to consider the whole thesis and its contribution to clinical practice and to research.

I believe that the work outlined in this thesis meets the requirements of a PhD to contribute 'new knowledge': in the form of the new prevalence data on depression in primary care patients identified in Chapter 2, together with development of the Self-Integrity model outlined in Chapter 7. The use of a subtle realist approach has also supported a critical reflexive analysis of the strengths and limitations of knowledge in clinical care, and highlighted implications for expanding the notion of evidence-based practice. By replacing 'truth' as the single quality marker for knowledge with a greater focus on the strengths and limitations of the methods by which knowledge is constructed and used, we may encourage a more critical approach to the use of knowledge in clinical practice.

The work is deliberately grounded in primary care and my own experiences of primary care practice. Some of the ideas arising from this work, for example the disruptive effects of illness on the self, may already be an intuitive part of clinical practice of many GPs. My goal was to provide a theoretical framework by which intuitive practice can be made more explicit. Whilst I might question the appropriateness of a notion of evidence-based practice which focuses only on pathological accounts of illness, I welcome the drive to support reflexive practice. This thesis contributes to the evidence base supporting development of patient-centred care, where individualised assessment of need can be supported by access to a range of therapeutic options.

The work has also highlighted the importance of understanding the cultural context and impact of medicine and medical care. I have indicated the importance of doctor-patient interactions in both potentially supporting and undermining emotional health. This area is of particular concern and relevance to primary care where questions of personal care and continuity of care are part of a traditional model of primary care but with still a limited 'evidence base' to support development of, and prioritisation of, these aspects of care. The Self-Integrity Model offers the potential for development of evidence based practice and policy within a primary care model of care.

I have discussed the individual limitations of both the quantitative and qualitative studies in Chapters 3 and 9. The broader limitations of the thesis perhaps lie in the choice of theoretical perspectives within which to study the lived experiences of patients. This is undoubtedly the biggest example of the impact of me as the researcher on the knowledge produced in this thesis. However in my defence, I do not offer the results as an absolute or universal 'truth'. I have endeavoured to be honest and critical about the process by which the knowledge in this thesis has been 'constructed'. I offer it as one approach to understanding illness experience which may have demonstrable utility in primary care practice; however like all knowledge, this needs further testing in clinical settings to assess its utility. Although I have endeavoured to demonstrate that I have met Maxwell's criteria for trustworthiness, the final criterion of utility is however not demonstrable within the setting of the current research project. I can make some inferences based on the data and my own knowledge of general practice. However the utility of my research can only really be determined over time and with future research.

I have questioned the current emphasis on using 'truth' as a marker of quality when assessing knowledge claims, yet caution must be urged in undermining a knowledge base without awareness of the importance of knowledge in social functioning (Dant 1991, Lee 1987). There are risks in removing an absolute standard by which to judge knowledge. 'Truth' is a concept that has strong ethical resonance within western society; many patients might baulk at the thought of their doctor working within a framework where 'truth' is 'not important'. There is a risk it undermines trust. However, conversely, the approach advocated in this thesis offers scope for a broader notion of truth (or even truths) which can therefore accommodate the truth of an individual patient's worldview within the broader health perspective.

10.6 Conclusions

A review of the whole thesis emphasises the need to focus on knowledge and practice. I have suggested that personal epistemology (understanding of the nature of knowledge) may be crucial in determining health outcomes of interactions, and even health in patients. I have highlighted that a wide knowledge base offers the potential for more patient-centred care, but still meeting the criteria for critical and judicious use of knowledge in evidence-based practice. It contributes to a knowledge base that is fit for purpose.

This chapter marks the end of the search outlined at the start of this thesis, and the beginning of a new more focused quest to contribute to development of a knowledge base which adequately informs clinical practice. The work offers potential to meet the health care needs of patients in General Practice, but I hope will also support the work of the health care professionals delivering that care.

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Appendix A1: Ethics approval

Liverpool (Adult) Local Research Ethics Committee
Hamilton House
24 Pall Mall
Liverpool
L3 6AL
Tel: 0151 285 2097
Fax: 0151 236 4493

Our Ref: 03/08/137/A

PRIVATE AND CONFIDENTIAL

Dr J Reeve
25 Bryanston Road
Liverpool
L17 7AL

9 October 2003

Dear Dr Reeve

Re: Mental Health Needs in Patients with Advanced Metastatic Cancer - Implications for Primary Health Care Teams

Thank you for responding to issues raised by the Committee, which were reviewed by Chairman's Action as agreed at our meeting of the Liverpool (Adult) Local Research Ethics Committee (LREC) on Wednesday, 3 September 2003. I am pleased to inform you that no ethical objection has been found and approval has now been granted with effect from 7 October 2003.

The Trust or appropriate Health Service Authority must be asked for permission for the study to proceed. Please contact Mrs Beverley Harrison, Clinical Quality Facility (Research), Hamilton House, 24 Pall Mall, Liverpool, L3 6AL.

The following documents were reviewed:

- Application Form
- Consent Form
- Patient Invitation Letter
- Patient Information Sheet
- Draft GP Letter
- EDS Questionnaire
- Revised Clinical Interview Schedule (Full Version)
- Revised Clinical Interview Schedule (Condensed Form)
- Semi Structured Interview: Draft Prompt Guide
- Post Interview Questionnaire (Finalised)
- Study Protocol
- Curriculum Vitae – Joanne Lucy Reeve
- Revised Patient Information Sheet
- Emailed Response from Investigator, dated 7 October 2003

Conditions of Approval

(a) The Liverpool LREC shall grant ethical approval for 3 years from commencement of study.

(b) Where it is felt appropriate, the Liverpool LREC may suspend or withdraw ethical approval (if, for example, the procedures being performed differ significantly from the agreed protocol) and notify the appropriate NHS body of this.

(c) Applications deemed to fall under the following category may be dealt with by Chairman's Action:

> "Investigations that pose no ethical problems, and are without risk of distress or injury, psychological or physical, to the subject, e.g. some epidemiology, some surveys of the public's eating or smoking habits, assessment of patient information and education, should nevertheless be the subject of an application but may be expeditiously handled by Chairman's Action "

(d) In accordance with ICH GCP Guidelines, an annual study update must be provided to the Committee. Failure to file the annual report by the due date will result in automatic suspension of the study without further notice.

(e) A copy of the final report must be submitted on completion of the study.

(f) All serious adverse events must be reported promptly to the Committee.

Any proposed amendments to the protocols must be notified to the Liverpool LREC for approval before implementation.

Liverpool LREC is fully compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH) Guidelines.

Yours sincerely

Dr T S Purewal
Chairman
Liverpool (Adult) Research Ethics Committee

Appendix A2: Invitation Letters

A2.1 Invitation letter to GP Practices

University of Liverpool
Division of Primary Care
Whelan Building
Liverpool L69 3GB
0151 794 5609

Mersey Primary Care Consortium

Dear [Name – Senior Partner/Practice Manager]

Mental Health needs in patients with advanced cancer – implications for primary care teams

Mersey Primary Care R&D Consortium is supporting a new research project being funded by the Department of Health. We are am hoping that you and your Practice will be interested in being involved with the study, and are writing to briefly give you an idea of what the study is about and what it might mean for your Practice.

Recent studies have suggested that at least one in four patients with advanced cancer suffer from depression. Not only does depression lead to reduced quality of life for the cancer sufferer and their family, but it also makes it harder to treat physical symptoms such as pain. Research has shown that antidepressant treatment can be effective in treating both depression and physical symptoms even within the last 4-6 weeks of life.

Yet we are all aware of the range of 'non-physical' health needs within this group of patients – including psychological, emotional and spiritual health needs. Much of the existing research looks at just one aspect of a patient's health needs (such as depression). But there are no studies undertaking a comprehensive assessment of patients' own perceptions of their mental, emotional and spiritual health needs.

In this study, we hope to conduct in depth interviews with patients with advanced cancer. This will allow us to produce a rich description of the experience of 'being depressed' as seen though the eyes of those patients. We will also explore their other concerns and needs and thus investigate how 'expert' defined mental health needs (a diagnosis of depression) compares with patients' descriptions of their needs.

The study will contribute to a better understanding of the experiences and mental health needs of this group of patients. It will lead to development of future research looking at ways to address those needs, and thus improve the care of patients with advanced cancer who are managed in primary care.

We are hoping to contact patients registered with your Practice to invite them to join the study. With your permission, Joanne would come to the Practice and identify which of your patients would be eligible to join. She would then be responsible for all the administration involved. We would only ask that you sign a covering letter sent to patients. All costs would be met by the research project. The patient will be asked to return the initial screening questionnaire directly to us.

Liverpool Research Ethics Committee have reviewed and approved the study (ref 03/08/137/A).

At this stage, we are simply trying to identify which Practices might be interested in joining the study. For those expressing an interest, Joanne will arrange to visit you and explain the study in more detail. We would therefore be grateful if you could complete the attached form and return it in the enclosed SAE. Filling in this form does not commit you to being involved, but simply states that you would be interested in hearing more.

We believe this is an important study that has the potential to help us provide the best possible care to meet the needs of patients with advanced cancer in primary care. We do hope you will be able to be involved.

We look forward to hearing from you.

A2.2 Invitation letter to patients

PRACTICE NOTEPAPER

Dear

[Name of practice] is taking part in a local research study which is trying to find out more about what type of help and support is needed by people who have cancer. We already know that people often have worries and concerns, but we would like to know more about how people feel so that we can provide the best sort of care for you and your families. To do that, the researchers need to talk to as many people as possible so that we can hear a wide range of views.

I am writing to invite you to take part in the research study. With this letter is a leaflet which tells you more about the study to help you decide whether or not to take part. The leaflet tells you more about why we are doing the study and also how you can take part. As it says in the leaflet, we are asking you to fill in a very short questionnaire (included with this letter). You may then be also asked to take part in an interview. Dr Joanne Reeve, a local GP who also works at the University of Liverpool, will be responsible for collecting the questionnaires and will be the person doing the interviews.

Please take as much time as you need to read the leaflet and discuss it with your friends and relatives or your GP here at the Practice. If there is anything you do not understand or would like more information about, please don't hesitate to ask Joanne. Her contact details are:

Dr Joanne Reeve
Department of Primary Care, University of Liverpool
Brownlow Hill
Liverpool L69 3GB
Tel : 0151 794 5609 Email: Joanne.Reeve@liv.ac.uk

If you would like to take part in the study, please sign the enclosed consent form and then complete the short questionnaire. Both forms should then be returned to Joanne in the stamped addressed envelope enclosed.

5. What are the benefits of taking part?

By taking part, you can help us find out more about the needs of patients with cancer. This will help us make sure we develop better services to help other patients like you. Although the overall research findings may not help you directly, other people with cancer who have taken part in similar studies have said they have found it helpful being involved.

6. Are there any downsides to taking part?

The questionnaire is very brief, but if you are asked to take part in an interview with Joanne, this may take between 30 and 90 minutes of your time. The questions will ask you about how you feel and, for some, your experiences of health services.

7. What will happen to the results of the study?

The results will be used in Joanne's research and will form the basis of a report that will be sent to key people responsible for local health care. It will also be published in national and international journals and presented at research meetings so that as many people as possible can hear about and benefit from the findings.

No report will include any personal details about any of the people taking part in the study.

8. Who is responsible for the study and who else is involved?

The Department of Health is funding the research. Joanne Reeve is the lead researcher, supervised by Dr Mari Lloyd Williams and Professor Chris Dowrick at the University of Liverpool. Ethical approval has been obtained from Liverpool Research Ethics Committee.

Appendix A3: Patient Leaflet

Emotional Health in Patients with Cancer

Invitation to join a research study

Patient information leaflet

For more information, please contact:

Dr Joanne Reeve

Department of Primary Care

University of Liverpool

Whelan Building

Brownlow Hill

Liverpool L69 3GB

Tel: 0151 794 5609
Email: Joanne.Reeve@liv.ac.uk

1. The purpose of the study

Doctors and nurses know that having cancer can affect people's mood but we want to know more about people's feelings, worries and concerns so that we can provide the best sort of help and support for them.

Joanne Reeve is a local GP who also works at the University of Liverpool. She is hoping to find out more about these feelings using a questionnaire and talking to people who have cancer.

2. Why have I been chosen?

Your GP Practice has joined this study. All patients registered with the Practice who are over 18 and who have cancer are being invited to take part in the study. We are keen to talk to as many people as possible so we can hear a wide range of views. There are a number of Practices in Merseyside involved. In total, about 250 patients will be involved in the study over a 3 year period.

3. Do I have to take part?

It is entirely your choice whether or not you would like to take part. If you do decide to join the study, you will be asked to sign a consent form. You will be able to leave the study at any time, (even after you have signed the consent form) and you do not need to give a reason. Whatever you decide to do, this will not affect any your medical care.

4. What will be involved if I do take part?

If you do want to be involved, we would ask you first to complete the short questionnaire enclosed with this letter. This asks you a few questions about how you feel cancer has affected your life and your mood. You will then need to return the completed questionnaire and the consent form in the stamped addressed envelope enclosed.

About half of you will then be asked to meet Joanne to answer some more detailed questions about your feelings and your mood. The interview will last about 30 minutes and will take place at a venue convenient for you.

Some of you will also be asked to take part in a longer interview including questions about your experiences of having cancer and the health care you have received. These interviews will be tape recorded so that Joanne doesn't have to take notes when she is talking with you, and instead can concentrate on hearing what you have to say. They will then be typed up and the original tapes destroyed.

ALL INFORMATION WILL BE IN STRICTEST CONFIDENCE.

Joanne will be responsible for making sure the tapes, transcripts and questionnaires are kept safe and away from people who should not see them. The only other people who may see or hear them are other people involved in the research project (Professor Mari Lloyd Williams, Honorary Consultant in Palliative Care; Professor Chris Dowrick, Professor of Primary Medical Care at Liverpool University).

Appendix A4: Consent form

UNIVERSITY HEADED NOTEPAPER

Title of project: Emotional health in patients with cancer
Name of researcher: Joanne Reeve

Please initial box

I confirm that I have read and understood the information sheet dated for the above study ☐

I understand that my participation is entirely voluntary and that I am free to withdraw at any time without my medical or legal rights being affected. ☐

I understand that sections of my medical notes may be looked at by Dr Joanne Reeve where it is relevant to my taking part in this research. I give permission for this. ☐

I understand that if I take part in an interview, it may be tape-recorded. I give permission for this ☐

I agree to take part in the above study ☐

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Appendix A5: Edinburgh Depression Scale

Name:

Address:

Date of birth:

The questionnaire asks you to say how much you agree with 10 statements. Please answer all the questions. Place a tick next to the answer which comes closest to how you have felt IN THE PAST 7 DAYS, not just how you feel today.

1. I have been able to laugh and see the funny side of things

As much as I always could [ ]
Not quite so much now [ ]
Definitely not so much now [ ]
Not at all [ ]

2. I have looked forward with enjoyment to things

As much as I ever did [ ]
Rather less than I used to [ ]
Definitely less than I used to [ ]
Hardly at all [ ]

3. I have blamed myself unnecessarily when things went wrong:-

Yes, most of the time [ ]
Yes, some of the time [ ]
Not very often [ ]
No, never [ ]

4. I have been anxious or worried for no good reason:-

No, not at all [ ]
Hardly ever [ ]
Yes, sometimes [ ]
Yes, very often [ ]

5. I get a sort of frightened feeling as if something awful is about to happen

Very definitely and quite badly [ ]
Yes, but not too badly [ ]
A little, but it doesn't worry me [ ]
Not at all [ ]

6. Things have been getting on top of me

Most of the time and I haven't been able to cope at all [ ]
Yes, sometimes I haven't been coping as well as usual [ ]
No, most of the time I have coped quite well [ ]
No, I have been coping as well as ever [ ]

7. I have been so unhappy that I have had difficulty sleeping

Yes, most of the time [ ]
Yes, quite often [ ]
Not very often [ ]
No, not at all [ ]

8. I have felt sad or miserable

Yes most of the time [ ]
Yes, quite often [ ]
Not very often [ ]
No, not at all [ ]

9. I have been so unhappy, I have been crying

Yes, most of the time [ ]
Yes, quite often [ ]
Only occasionally [ ]
No, never [ ]

10. The thought of harming myself has occurred to me

Yes, quite often [ ]
Sometimes [ ]
Hardly ever [ ]
Never [ ]

Appendix A6: Semi-structured Interview Schedules

A6.1 First draft February 2004

- How are you feeling at the moment?
- Can you tell me about when you were first told you had cancer
- What were your thoughts and feelings when you were first told you had cancer?
- Have they changed since then and if so how?
- Thinking about all aspects of your health (prompts: emotional, physical, social, mental, spiritual) how would you describe your health at the moment?
- What sorts of things/experiences make you feel better?
- What sort of things/experiences make you feel worse?
- How would you describe your mood at the moment?
- Have you felt depressed at any point since being told you had cancer?
- How does it feel to be depressed? (prompts – mood, feelings, thoughts, hope, physically/function, relationships with others, control) OR Can you think of somebody you've known/met who was depressed – what were they like?
- Have (did) you spoken (speak) to anyone about how you feel (felt)? (Prompts - who? Why them? What was the outcome)
- Who do you look to for help with your health and well being? (Prompts - family/friends/health care services/ voluntary groups / religious groups / others).
- How do each of those help you? How successful has their help been?
- Is there anything more that you feel that would have helped or would help you now in dealing with your health (prompts – mental emotional psychological spiritual social health)

A6.2 Final draft by end of project

Can I start by asking you how you are feeling at the moment?

Can you tell me your story – what has happened since you were diagnosed with cancer?

AIM: To encourage reflection on all stages of the process
To identify the factors that influenced interpretation/conceptualisation
To identify feelings/emotions associated with the process

Prompts:
* *Feelings*
* *WHY do you think that was – TELL ME ABOUT IT*
* *WHAT influenced that*
* *CHANGES in how feel/perceive/understand situations*

Follow up if not already covered:

- What things (situations, interventions, whatever) affect your health and well being – make it better or worse.

- Have you felt depressed at any point since being told you had cancer? How does it feel to be depressed? (prompts – mood, feelings, thoughts, hope, physically/function, relationships with others, control)

- Have you ever felt lonely – tell me about it

- What aspects of your life are most important to you? (What are the good bits and the bad bits?) Has having cancer changed how you think about your life, and if so how? WHY or WHY NOT?

- Some people I have spoken to have described some aspects of life as being easier now – life being more free. Would you agree?

- Are you worried or frightened about anything at the moment? Do you worry about dying or about what will happen after you're dead? Why?

- People sometimes talk about finding 'peace of mind'. Does that mean anything to you? Tell me about it (Prompts: Fear, how it feels, changes in experience, how to find PoM)

- Does faith or spirituality play a part in your life? In what way? Can you tell me more about that?

- How well do you think other people (for example your family & friends, hcp, acquaintances) understand how you are feeling – about the cancer or more generally? Why? What impact does that have on you, if any?

- When bad things have happened in your life, how have you dealt with them?

Appendix A7: Describing the analysis process

Given the emphasis in this thesis on an open and reflexive approach to knowledge production, here I describe an account of the iterative analytical process leading to the results presented in Chapters 6-8. By offering a chronological account of the analysis process, I aim to describe how I reached the results presented in the main body of the thesis and thus open up my analysis for critical review. The account is based upon notes in my research diary and on written documents produced during the research either as summaries for myself, for my supervisors, or for presentations (as listed in appendix A8).

A7.1 Getting started

Reflection and analysis were an integral part of data collection. However formal coding of transcripts began once I had completed four interviews (although one of these interviews was not subjected to further analysis as the participant was found not to have terminal illness). At this point, I had not identified any examples of Biographical Disruption. I therefore proceeded with open coding of the three remaining texts (Ron, Helen and Angela) to start to identify emerging themes that related to emotional experiences since the terminal cancer diagnosis. Coding was done on paper transcripts, marking comments and codes in the margin. The transcripts and emerging themes were shared with Professors Lloyd-Williams and Payne to confirm we were all identifying common areas of text as important, and to begin to discuss the interpretation of emerging ideas.

I then proceeded to a detailed open coding of one transcript (Angela) using NVIVO (version 1.3). Where possible, "in-vivo" codes where used which reflected the words used by the participant (Strauss & Corbin 1998: 105). This coding was primarily descriptive rather than interpretive, simply seeking to capture the breadth of experiences expressed within the interviews. Field notes were also collected throughout the analysis process, detailing thoughts on the possible meanings associated with the identified descriptive codes. For example, the following section was descriptively coded as ADDEFF – tmt (Adverse Effects – of treatment):

> Angela: *"All the side effects that you have plus a few extra. I mean the side effects of the first chemo were very severe because it was a double whammy...Taxol is a fairly new drug. It does have some pretty mega side effects."*

With an added field note written by me (taken from my research diary):

> Coding field note, JR: *"This is established to tell us what she has overcome – part of the story of how she has coped: establishing her own credibility and adding weight to her story."*

All experiences or interpretation of thoughts, feelings and emotions as a consequence of the cancer diagnosis were included in the open coding. This resulted in an extensive (>60) list of predominantly descriptive codes. Some initial attempts to group similar codes into broader themes still resulted in a complex coding structure. A summary is shown in table A7.1.

Table A7.1: Summary of open coding arising from an in-depth analysis of Angela's transcript (May 2004)

Category	**Themes**
Competent Adult (self)	*through* practical behaviour; knowledge
Physical health	Variable; treatment effects on health; perception of health
Health Care Professional Attitudes	Feeling cared for (care, competent, trust), fear
Ideas	Cognitive dissonance, lonely, altered worldview
Feelings	Disappointed, down, frustration, stigma, shame, fear, satisfaction
External locus of control	Cause of disease (not my fault), physical aspects, responsibility (legitimate deviance)
Internal locus of control	Sense of self/coping, expert (self, credible), healing, dignity, treatment
Coping	*through* knowledge, goals, flexibility, planning, hope, humour, active acceptance (collusion), diversion
Altered worldview	Self (priorities, selfish), others, work, social impact

Category	Themes
Uncertainty	About disease, negative experience, from health care process
Reduced constraints	Freedom, reduced barriers, a reward (for what given up)
Cared for	Comfort, special, share burden, empathy, reduced responsibility, talk, touch

I subsequently applied the emerging coding structure to the other two transcripts (supported by the use of the NVIVO version 1.3). Many existing themes (codes) were identified in the other interviews, but new codes also emerged. I attempted to write a narrative account of the emerging analysis in order to share my thinking with my supervisors, but found it impossible to produce a coherent account even of the 3 transcripts. The coding structure was increasingly unwieldy. It became apparent that codes were not adequately defined: there were significant problems with duplication of ideas and overlapping themes. The coding structure was descriptive and not explanatory. I therefore returned to the theoretical literature for ideas that might help me better understand the emerging ideas.

A7.2 The emerging self

At this point, I interviewed Peter. In the early stages of the interview, I was concerned that he might not be aware of the prognosis of his illness. His account was about his time fell-walking and how important it was to him. His speech and body language was animated. Even as it became apparent that he was fully aware of the terminal nature of his illness, and that he would never fell-walk again, the commitment and enthusiasm in his narrative remained. I spent some time reflecting on this interview and trying to understand what I had been told. My interview diary on 20th September 2004 notes:

> Field notes, JR: "*My list of codes is long and predominantly descriptive. I am not getting to the heart of what and why... My interview last week with Peter made me question. Here was a man who superficially hasn't come to terms with what*

> *is going on. He talked constantly about fell walking – something he can't do because of his metastatic prostate cancer. But what he was talking about was himself, the essence of his 'sense of self' and what was important to him. It was as (?) important to have that acknowledged (ie me listen in contrast to his oncologist) as for him to be doing [fellwalking]."*

I thus identified 'the self' as the primary focus in Peter's interview, and noted that similar ideas were embedded in the existing coding structure. I therefore reviewed the analysis of Angela placing 'the self' at the heart. I identified positive and negative emotional pulls on 'the self', although what I meant by 'the self' was still not clear. My coding structure of 2/6/4 commented that 'the self' lies at the heart of wellbeing. However I also questioned whether this was 'real' or created by the research process. The coding structure at that stage is shown in Box A7.1.

Box A7.1: Revised coding structure for Angela

SELF
Role; wellbeing

NEGATIVE FEELINGS

UNCERTAINTY
- Feeling (lonely, panic, down)
- Why (disease, function, healthcare)

FRUSTRATION
- Feeling
- Why (others, uncertain, physical)

STIGMA
- Feeling; Why; Control

DISEASE & DYING
- Fear; Why (process, loss, family)

POSITIVE FEELINGS

COPING
- Control, active acceptance, flexibility, diversion

CONTROL
- Internal control
- Share burden

REDUCED CONSTRAINTS
- Barriers, freedom, expectn

LOOKED AFTER(cognitive)
- Reduced responsibility

CARED FOR (emotional)

My concerns over what I meant by ‘the self’ prompted a return to the theoretical literature, and philosophical and sociological accounts of the self. I also remained concerned by the repetition in the coding structure identified in box A7.1, which I still felt was descriptive rather than explanatory. I had also by now identified my first case of Biographical Disruption, and was therefore looking to explain why people's biographical experiences differed. I therefore turned to new transcripts to explore positive and negative effects on the self, also seeking to explain why the process led to different experiences for different people (ie Biographical Flow or Disruption). I started a new open coding process using one existing transcript (Helen) and two new ones (Nora, Jenny).

A7.3 Moving from description to evaluation

The outcome was the identification of a ‘narrative process’, identifying a sequence of events shown in Figure A7.1.

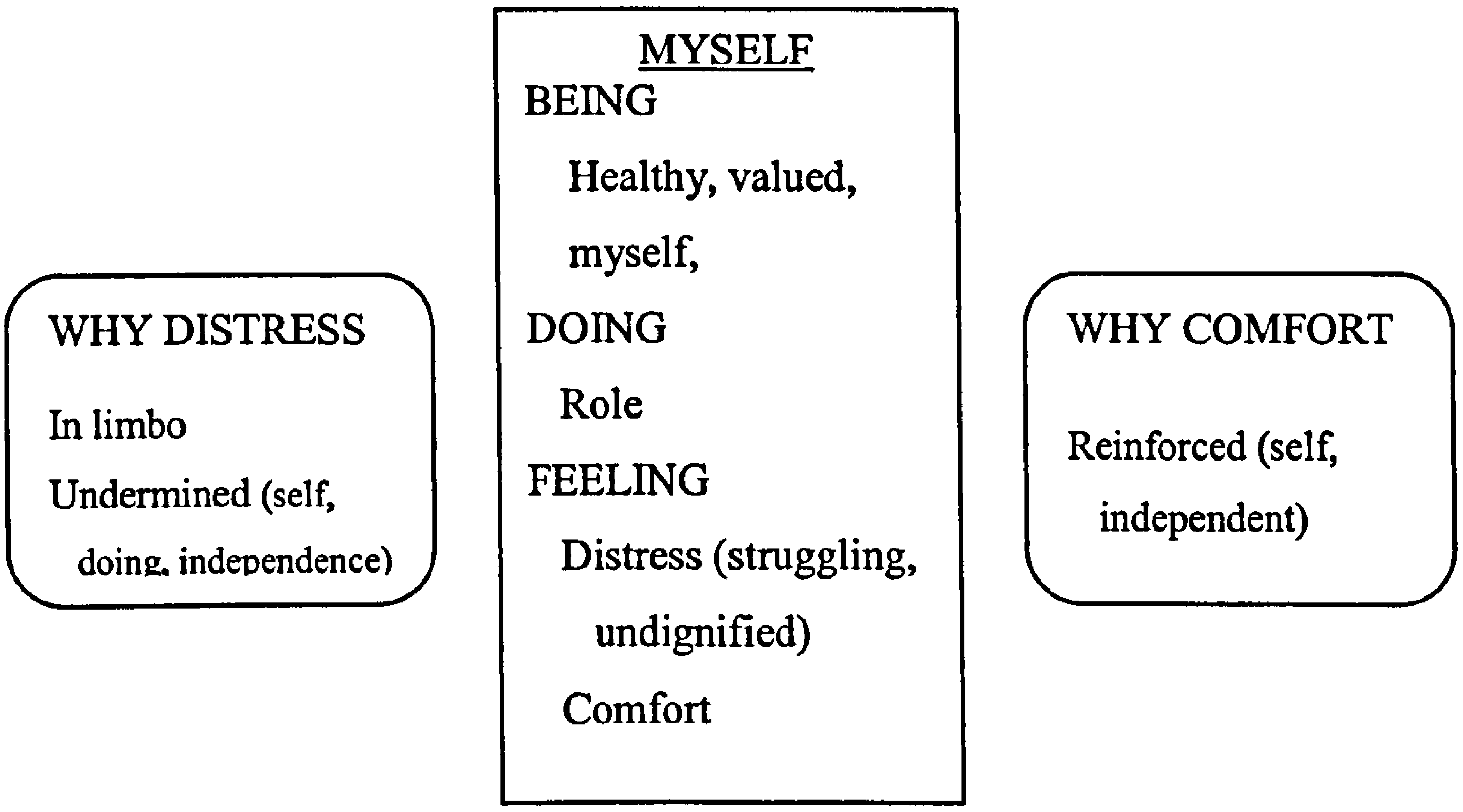
Figure A7.1: Showing the sequential effect of life events on the self

INSULT → SELF → RESPONSE → OUTCOME

‘Insults’ came from uncertainty, external events ‘done to me’, and internal perceptions of the self. ‘The self’ remained undefined at this stage of the analysis; it was recognisable in the data but I was finding it clarify what the essential elements of that self were. ‘Responses’ included reflection, withdrawal and normalisation of experiences; all of which could be done alone or shared. ‘Outcomes’ were resolution or decline.

The emerging ideas were used to modify the interview schedule. However I was still concerned that although an idea of ‘the self’ was present in each interview and therefore central to the emerging analysis, I was still unable to adequately describe what I meant by the idea. In particular, I struggled to capture the common threads across all the interviews. I therefore decided to focus on one category (that of Biographical Flow) in order to focus on what ‘the self’ might be. By revisiting transcripts (Helen, Peter) and including new ones (Albert, Ron, Nora, Mary, Joyce), I identified a descriptive account of the self as including themes of 'being', 'doing' and 'feeling'. An account for Joyce produced in July 2005 is shown in Box A7.2.

Box A7.2: Coding structure for Joyce, July 2005



I found that I was getting tangled up in philosophical debates on the nature of the self that were taking me away from my data. Fortunately at this stage of my analysis, I was beginning to try and present my ideas to external audiences at conferences. This helped shift my gaze from complex questions about what is the self to a consideration of how to explain the differences I was observing in my data. (This after all was the intended aim of my methodological stance: not to determine 'what is', but what things are experienced differently).

Having realised that Angela's account was qualitatively different to others identified as Biographical Flow, I had now identified three categories of experiences: Biographical

Disruption, Flow and Shift (see Chapter 5). The 'self' seemed to be similar in all; explanations for differences lay elsewhere. I therefore returned to the Insult – self – response model to seek to understand why people were able to maintain continuity. In September 2005, I had identified key themes and a coding structure to explain the experience of Biographical Flow which is shown in Box A7.3.

Box A7.3: Coding for Biographical Flow (September 2005)

ACCOUNT OF SELF: being, doing

INSULT: cancer diagnosis

MECHANISMS FOR MAINTAINING CONTINUITY:
Internal – strong sense of self, reflection, adaptive, emotional release
External – release from constraints, frame of reference outside the self (eg faith), shared narrative

These steps could be identified for all the interviews in the Biographical Flow group; I felt I was starting to move towards a point of coherence. However, a number of problems were still identifiable. My analysis didn't adequately explain the emotional experiences identified in my data. The model also still couldn't adequately explain the categories of Biographical Disruption and Shift. I tried to undertake a cross-case analysis based on the themes identified in box A7.3; comparing cases within and between biographical categories (using an Excel spreadsheet to facilitate comparison). This once again highlighted the lack of clarity in defining the concepts with sections of the data either being duplicated or missed out of the resulting analysis. I identified a problem with my conception of the self: a key component at the heart of the emerging analysis. In particular I realised I had started to assume a narrative understanding of the self. Although supported by theoretical and empirical findings in the literature, it couldn't adequately explain my data.

Following a prolonged period of reflection and re-analysis of the data, I identified what I felt was the essence of the self described in all the interview narratives. I labelled this as the 'core-self', and described it as an inner existence which we know through our 'narrative self', but is also revealed through (and indeed perhaps shaped by) our emotional experiences of life and life events. I therefore sought to understand the impact of life events on these aspects of the self, and thus explain the three observed biographical categories. Based on cross-case and cross-category analysis, I developed the model shown in Figure A7.2.

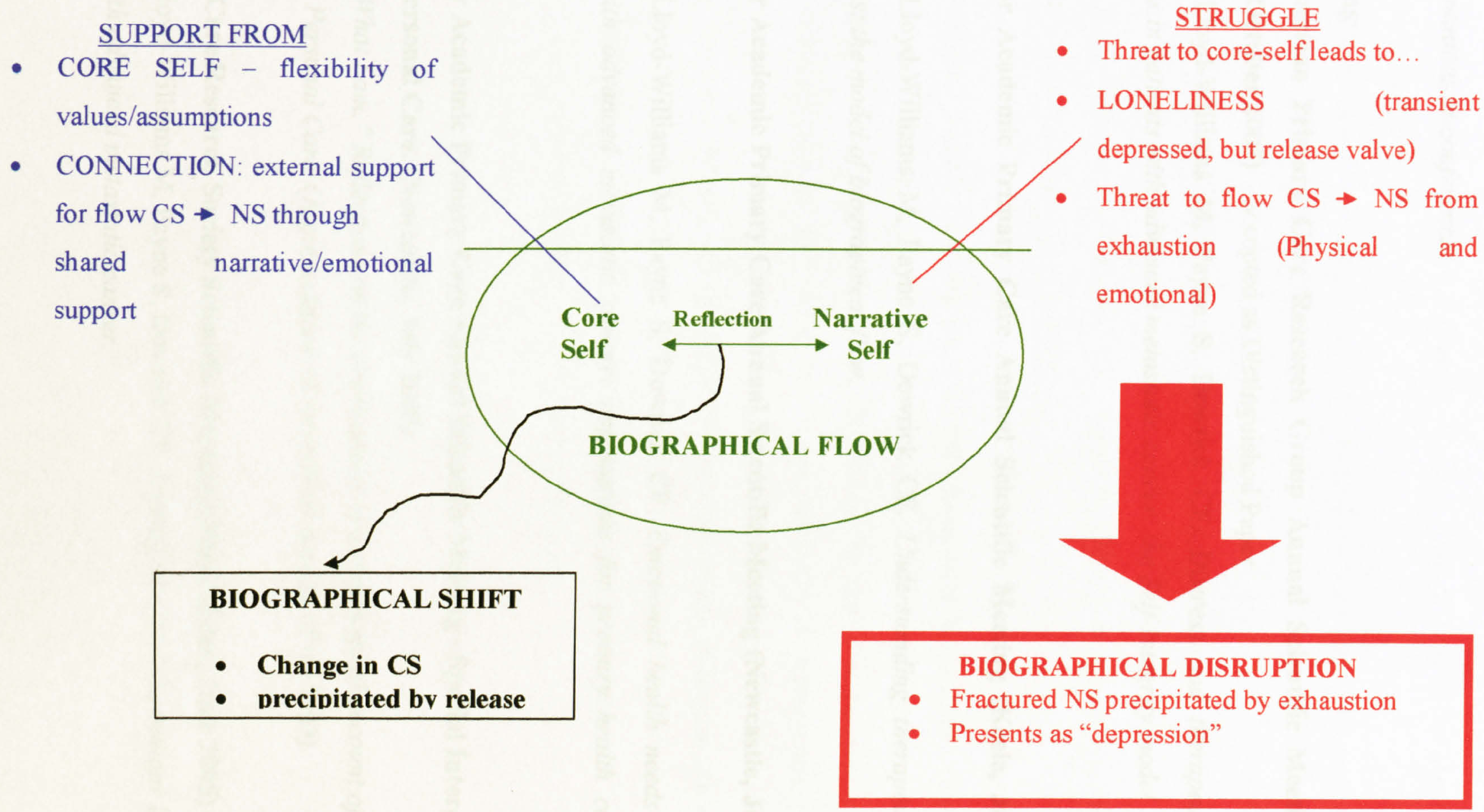
A7.4 The final version

I refined the emerging analysis through attempts to write narrative accounts of the data in the form of draft chapters of my thesis. Attempting to write a coherent account of the model revealed unchallenged or unsupported assumptions. The whole process involved continuously revisiting the data to test whether new ideas could hold. Eventually I identified 4 key themes which I could defend from the data: the core-self (as what mattered to people), threats, the results of threats and balances. The full Self-Integrity model which arose from this is described in chapter 7. Given that the biographical categories were instrumental in identifying the final framework and also part of the original theoretical stance, a description of these were used to frame the account, as detailed in Chapter 6.

A7.5 Looking at depression: the dangers of preconceptions.

When first designing this study, one intention had been to compare biomedical and lay accounts of the experience of depression. However, low levels of ICD-defined depression were identified in the prevalence survey from which the qualitative sample was drawn. Depression was also revealed as a relatively minor theme in the interview data. There was considerable overlap between areas of text coded as 'depression' and other areas such as frustration and unfairness. The qualitative analysis suggested that depression was not a unique phenomenon in itself, nor one that was a significant part of people's experiences. Early on in the analysis, I felt I was trying to 'force' data into a code ('depression') which I then struggled to fit back into the bigger picture that was emerging from peoples' accounts. Eventually I realised that the problem lay in trying to understand a phenomenon (depression) that wasn't part of the world of my study participants. I therefore identified the need to shift my focus onto the phenomenon that people offered me in their interview accounts - that of the impact on themselves and the emotional experiences related to this. The newly identified phenomenon was therefore the emotional experiences associated with the impact of diagnosis on people's sense of self. The reflexive approach described in this appendix and in the preceding chapters was crucial in supporting the identification of this and other assumptions which were causing difficulties with the analytical process.

Figure A7.2: Summary of core themes from qualitative analysis (January 2006)



Appendix A8: List of presentations

Oral presentations at conferences

Forthcoming:

North American Primary Care Research Group Annual Scientific Meeting (Arizona, October 2005) - accepted as Distinguished Paper
Reeve J, Lloyd-Williams M, Payne S, Dowrick CF. *Distress and therapeutic interactions in patients with advanced metastatic cancer: the Self-Integrity model*

Completed:

Society for Academic Primary Care Annual Scientific Meeting (Keele, July 2006)
Reeve J, Lloyd-Williams M, Payne S, Dowrick CF. *Understanding therapeutic interactions: the model of biographical flow.*

Society for Academic Primary Care Annual Scientific Meeting (Newcastle, July 2005)
Reeve J, Lloyd-Williams M, Payne S, Dowrick CF. *Emotional health needs of patients with advanced metastatic cancer: implications for primary health care teams.*

Society for Academic Primary Care Annual Scientific Meeting - Special Interest Group: Personal Care. (Newcastle, July 2005)
Reeve J. *"What I am." Reflections on the implications of a sociological account of the self for Personal Care.* (A presentation of theoretical aspects of my PhD)

Palliative Care Research Society Scientific Meeting, (Manchester, June 2005)
Reeve J, Lloyd-Williams M, Payne S, Dowrick CF. *Linking stories and emotions in patients with advanced metastatic cancer.*

Poster presentations at conferences

North American Primary Care Research Group Annual Scientific Meeting (Quebec, October 2005)

Reeve J, Lloyd-Williams M, Payne S, Dowrick CF. *Linking stories and emotions in patients with advanced metastatic cancer*

Academic Palliative Care Study Group One day Scientific Meeting. (Liverpool, April 2005)

Reeve J, Lloyd-Williams M, Dowrick CF, Payne S. *Making sense of emotional responses to a terminal diagnosis of cancer.*

Medical Research Society Meeting for Clinician Scientists in Training (Royal College of Physicians, February 2005)

Reeve J, Dowrick CF, Lloyd-Williams M. Mental health needs in patients with advanced cancer: implications for primary health care teams (Work in progress).

Society for Academic Primary Care Annual Scientific Meeting (Glasgow, July 2004)

Reeve J, Lloyd-Williams M, Dowrick CF. *Mental health needs in patients with advanced cancer – implications for primary health care teams.*