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Paul Beadon

Date: 14/08/2009

UNIVERSITY OF SOUTHAMPTON

**An Exploration of the Effect of a Life-limiting Diagnosis on an  
Individual's Relationship with their Body: A Qualitative Study**

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## GENERAL ABSTRACT

To date there has been limited research into the lived experiences of individuals with a life-limiting diagnosis, particularly with regard to the ways in which they make sense of, and ascribe meaning to, their experiences.

The first part of this thesis contains a review that evaluates the present literature on the lived experiences of individuals with a life limiting diagnosis. The review explores the types of narrative-based ‘meaning making’ processes that are generated by individuals experiencing life-limiting disease. The discussion is extended to specifically consider the ways in which disease related changes to the body impact upon narrative processes. The relationship between bodily experience and narrative identity is explored. It is identified that there is minimal empirical research investigating these experiences.

The second part of this thesis contains a qualitative research study, which aims to provide a rich account of 11 participants’ relationship with their body in the light of their life-limiting diagnosis. Participants were interviewed about their relationship with their body and Interpretive Phenomenological Analysis was applied to the interview transcripts. The analysis yielded eight over-arching themes and 24 higher-order themes.

Themes that emerged from the data included: the experience of the changed body, fear of the body’s future, threats to the individual’s sense of ownership of the body within the context of the medical encounter, and adaptivity to disease. Discussion of these constructs focussed on the experience of embodiment that can be seen to underlie participants lived experience of disease.

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## **Literature Review**

### **Narrative Processes of Meaning -**

#### **Making when faced with a Life-limiting Diagnosis:**

#### ***Relating to Dying, Disease and the Body***

*Running head:* Relationship to the body-with-disease

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This paper was prepared as if for publication in *Narrative Inquiry*<sup>1</sup>

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<sup>1</sup> See Appendix A for the guidelines on author submissions to *Narrative Inquiry*

## Abstract

This literature review seeks to bring together and evaluate psychological literature pertaining to the ways in which dying individuals construct meaningful narratives when facing their death. This review extends this discussion to specifically consider the ways in which disease related changes to the body impact upon these narrative processes. This is placed within the context of modern palliative care.

Prevalent themes encountered in a dying individual's narrative are explored and the attempts of a number of academic authors at deconstructing the *types* of narrative that prevail are described and evaluated. It is argued that the type of narrative employed by an individual will directly impact upon the success with which meaning making processes facilitate a positive quality of life. The relationship between cohesion of the body and narrative cohesion is explored, specifically in relation to the concept of embodiment.

Finally, the importance of recognising narrative processes in order to facilitate adaptive story telling is discussed and the ways in which future research may be advanced from this discussion are considered.

Key words; narrative, meaning making, cancer, illness, dying, body, embodiment

## Introduction

“Dying is one of life’s unique experiences, ubiquitous yet largely unexamined.”  
(Yedidia & MacGregor, 2001, p. 807).

There are two great challenges to instigating any discourse about dying; firstly, it is for many a profoundly difficult subject to raise and, equally, for many others it is a frightening discourse to listen to. Yedidia and MacGregor (2001) propose that it is these emotional barriers which explain why psychological literature exploring the nature and personal meaning of dying people’s experiences is, to date, limited in scope.

The aim of this literature review is to bring together and evaluate psychological literature pertaining to the nature of dying people’s experiences, and specifically to the processes by which they imbue their experiences with meaning. The active, personal and social process of constructing new narratives while dying will be considered. The latter part of this review will consider the impact of the body-with-disease upon the development and expression of the dying individual’s narrative.

The literature included in this review was selected via two primary routes. Firstly, a literature search was conducted using the Psychinfo and Sciedirect databases (1985-present). Search terms included: narrative, meaning making, palliative care, cancer, illness, dying, body, embodiment, and body image. The author also consulted with numerous experienced clinicians and researchers specialising in palliative care

and narrative theory. This consultation produced a body of literature that encompassed empirical research and review articles as well as biographies and other forms of narrative written by individuals who had direct experience of a life-limiting diagnosis and/or a severe illness. The authors of these narrative accounts were often academics writing from the perspective of their respective disciplines, which included psychology, literature, sociology, history and philosophy.

This review begins by exploring the contemporary landscape of palliative and hospice care, which is the context within which this research takes place and serves for many (although certainly not all) as the backdrop to the experience of dying in the United Kingdom, the United States, and parts of Europe. It is from this culturally defined setting that most research is drawn and it is towards this setting that the findings of such research will be directed in attempts to improve end of life care.

### Death and Dying in the West

#### *Palliative Care*

The World Health Organisation (WHO) defines palliative care as:

“... an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

(Sepúlveda, Marlin, Yoshida, & Ullrich, 2002, p. 94)

Core aspects of the palliative care approach identified by WHO include; providing relief from pain and other distressing symptoms, affirming life and regarding dying as a normal process, neither hastening nor postponing death, integrating the psychological and spiritual aspects of patient care and offering appropriate support aimed at helping patients live as actively as possible until death (World Health Organisation, 2004).

In the United Kingdom palliative care emerged from, and is often synonymous with, the hospice movement that was started by Dame Cicely Saunders in the late 60's (Clark, 1999).

Across her career Cicely Saunders trained as a nurse, a social worker, and finally a physician, permitting her to develop an approach to care that drew from medicine and the social sciences and was informed by her years of close bedside contact with the dying and their families (Clark, 1999; Saunders, 2001).

A significant tenet of Saunders' approach was its objective of addressing 'total pain'. The emphasis of this approach is on recognising that 'pain' at the end of life is a more complex experience than a purely medical definition allows for, encompassing physical, emotional, social and spiritual dimensions of human experience (Clark, 1999; Higginson, 1993; and see Johnson, 1999, on biographical pain at the end of life). The hospice movement therefore arose as an approach that sought to more effectively address 'total pain', whilst also improving the quality of pain and symptom management (Clark, 1993).

The term ‘palliative care’ originated from the Canadian urological surgeon Balfour Mount. Following a visit to St Christopher’s Hospice, the founding hospice of Saunders’ approach to the care of the dying, Dr Mount returned to Canada to open the first Canadian hospice. However, as the local French culture used the term ‘hospice’ to refer to ‘a place of last resort for the poor’ Dr Mount coined the term ‘palliative care’ (or soins palliattifs) to be a synonym for hospice that would be acceptable to the English-speaking and French-speaking Canadians (Hamilton, 1995; Mount, 2003) and this term has now become widespread.

### *Where and How People Die in the West*

Over the past century there has been a shift in health trends and in patterns of disease, which has had implications for the ways that people are likely to die and the places that they are likely to die in (Field & James, 1993). Mortality due to acute disease has diminished considerably while chronic, degenerative diseases, including diseases of the circulatory and respiratory systems, HIV/AIDS and cancers, have become the primary cause of death (Field & James, 1993; Higginson, 1993). Field and James (1993) cite improvements in standards of living, nutrition and hygiene, as well as advances in medicine and in systems of care for these changing patterns of disease and mortality.

Currently people die in a variety of settings in the UK; these include their own homes, hospitals, residential homes, and hospices. The 2004 WHO analysis of end of life care indicated that the majority of people in the UK, the US, Germany, Switzerland, and France die in hospitals (World Health Organisation, 2004).

However, a review of 18 studies that sought to determine the preferred place of death for palliative patients found that the majority of patients indicated a wish to die at home, with a range of 49% - 100% of patients advocating this across the different studies (Higginson & Sen-Gupta, 2000). In practice only 22% of people actually do die at home, while around 4% die in hospices (National Audit Office, 2008).

Accordingly both the USA and the UK have invested in home care initiatives to address this, with the UK government investing £12 million in the NHS's end of life care programme between 2003 - 2006 (Gomes & Higginson, 2006).

It is important to note that the principles of palliative care are not limited to the physical boundaries of hospices, indicating the applicability of these principles to hospital care, home-care and day-care services (Saunders, 2001).

### *A Good Death*

The focus of palliative care can be said to rest upon maintaining an individual's *quality of life while dying*, permitting 'living in the face of death' (Kubler-Ross, 1997) but also seeks to provide a *quality of death* (Higginson, 1993; Higginson & Sen-Gupta, 2000)

The 'Future of Health and Care of Older People' report identified 12 principles of a good death (Age Concern, 1999), see Figure 1 below. Smith (2000) identifies the key themes of choice, control, and dignity within these principles.

### Principles of a good death

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs (at home or elsewhere)
- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual or emotional support required
- To have access to hospice care in any location, not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives which ensure wishes are respected
- To have time to say goodbye, and control over other aspects of timing
- To be able to leave when it is time to go, and not to have life prolonged pointlessly

**Figure 1: Principles of a Good Death (Age Concern, 1999)**

Clark (2002) supports these as excellent principles of a good death and further suggests that a good death is an “aware” death in which the dying have the opportunity to resolve ‘personal conflicts and unfinished business’ and where death is seen as an opportunity for personal growth (Clark, 2002, p. 907). Clark (2002) does not elaborate any further on these profound and complex issues of resolution and growth, however, these topics are central in understanding meaning making processes at the end of life.

### Meaning Making: Narratives to Live by

‘Meaning making’ refers to the ways in which individuals imbue their experience with a significance that is congruent with their worldview (Abes, Jones, & McEwen, 2007). Meaning making processes enable the individual to derive a sense of purpose and value in their life (Singer, 2004).

This review seeks to explore the literature that pertains to the ways in which dying people imbue their experiences with meaning and how these processes contribute to their quality of life. The discussion that arises from this review is built upon a narrative paradigm and a constructivist epistemology. Before advancing this discussion it is necessary to ground the literature review in the context of narrative approaches to meaning making more generally.

### *Narrative Psychology*

Narrative psychology claims that constructing narrative order from the procession of life's events is the primary form by which experience is made meaningful (Polkinghorne, 1988).

Narratives may be encountered in a vast array of forms, including literature (Berger, 1997), the media (Chatman, 2006) and cultural myths (Campbell, Cousineau, & Brown, 2003). Such narrative forms are often imbued with themes, belong to a genre, have a structure, reflect individual and cultural values, and tell a coherent story. Narrative psychology supposes that individuals use narrative conventions to story their life. In essence what story adds to the chaos of life is a coherent, meaningful plot (Bruner, 2004). This is what Taylor (1996) means when he writes:

“... our greatest desire, greater even than the desire for happiness, is that our lives mean something. This desire for meaning is the originating impulse of story.”  
(Taylor, 1996, p. 96)

Denzin (1989) summarises the key qualities that various authors (e.g. Bruner, 1990; Scholes, 1981) have identified as being essential to separate an individual's narrative discourse from other types of discourse. He suggests that a narrative discourse:

- Will have a beginning, middle and an end
- Will be linear and sequential
- Will have a plot
- Will make sense to the narrator
- Will be past orientated (that is the narrative will be retrodictive)

In regard to the stipulation that narratives are always orientated in the past, it should be noted that narratives do often incorporate hopes and fears about the future, or reference future goals and ambitions that build upon or validate the current state of a narrative 'plot'. So, while all narratives will be based upon a story structure with its roots in the past, they may extend to the future.

Polkinghorne (1988) observes:

"We are in the midst of our stories and can not be sure how they will end; we constantly have to revise the plot as new events are added to our lives."  
(Polkinghorne, 1988, p 150.)

Here Polkinghorne (1988) acknowledges a key feature of narrative theory, which is that stories are being continually restructured in the light of new experiences. Arvay (2001) argues that narrative construction and narrative re-construction, and the

extraction of new meaning from these changing narratives, is an active, ongoing phenomenon. The restructuring of narratives in the face of challenges will inform the discussion on narratives of the terminally ill later in this review.

### *Narrative Identity*

Self-concept is a product of the self-reflective nature of human cognition and is susceptible to change as the individual encounters new roles, situations, and life transitions (Demo, 1992; Kraus, 2007).

Various authors (Dennett, 1993; Gallagher, 2003; Ricoeur, 1988, 1992) have described how individuals live their lives by multiple narratives. For example, an individual may have developed various distinct narrative constructs that include:

- The narrative of being a parent
- The narrative of being a professional
- The narrative of being a husband
- The stories the individual likes to tell of himself or herself
- The plans the individual has for the future

This represents a postmodernist view of the self in which there is no such thing as a concrete ‘core self’ but instead a more fluid ‘self’, which is always ‘in flux’ (Arvay, 2001). However, if this is the case, how is it that people perceive themselves as possessing a consistent personality and sense of self between multiple situations and across the span of their lives?

Narrative theory suggests that the development and maintenance of a broad life-narrative (or meta-narrative) provides a much needed sense of ‘continuity of self’. This continuity is achieved through the rationalising nature of the evolving story; characters (including ‘the ‘self’ are given motivations and plot-based justifications are generated which are able to rationalise incongruity between past and present conduct, explain inconsistency across multiple situations and excuse differences between values and behaviours (McAdams, 1987, 2006).

### *Negotiating Narrative Identity*

An individual’s self-narrative is always entangled in the narratives of others (Ricoeur, 1992). Identity may arise from narratives constructed by the self that are about the self but it is significantly impacted upon by the narratives that others develop about an individual (Kraus, 2007). Therefore narratives can often be seen as co-authored in negotiation with others. The audience also has a role in accepting the authenticity of the narrative and may suggest or demand revisions. The creation of narrative identity is therefore interactive, dialogical and performative (Kohler-Riessman, 2004; Lucius-Hoene & Depermann, 2000). Narrative identities can also be shared across wider groups and the quality of these narratives will influence the cohesion and power-relationships of such groups (Roberts, 1999)

### *Neurology and Narrative Identity*

Narrative identity is reliant on a number of neurological systems, particularly those supporting learning capabilities and (episodic) memory systems (Gallagher, 2003).

One result of the capacity to learn is the acquisition of language. Narratives are made possible by language; they are generated using language, they are encoded and stored using language and they are manipulated and restructured using language. Language provides narrative with its scope and its limitations (Goncalves, 1997).

Gallagher (2003) cites the findings of various neuroscientists (for example Damasio, 1999) that describe the brain's functions as a collection of distributed neurological processes that have no clear neurological centre of experience. Gallagher (2003) argues that the brain, processing perception in this way, stands the risk of experiencing the world in a fragmented way.

Gallagher (2003) believes that the mind overcomes this by creating 'virtual selves'. These virtual selves are complex narrative constructs created using language and harnessed in memory and they act to unify the potentially fragmented awareness the distributed processes of the brain might otherwise cause. Gallagher cites Hume's (1975) work on the nature of human experience, which concluded that the self consists of a bundle of momentary impressions connected together across time with imagination. Gallagher (2003) suggests that this description is in keeping with neurological evidence and, further, he believes that narrative identity, encapsulated in these virtual selves, is the imagination that Hume (1975) refers to that connects the self together across time.

### *Memory's Role in Narrative Construction*

Alongside language, memory obviously plays an equally central role in the construction of narratives, most especially autobiographical memory, which represents an organisation of episodic memories into a coherent narrative.

Conway and Pleydell-Pearce (2000) put forward the view that any satisfactory account of autobiographical memory should incorporate a model of 'self' that recognises the interaction of personality traits and cognitive-affective processes upon encoding and organisation of memories into a goal-based hierarchy of autobiographical knowledge. Memories are therefore seen as organised (and loaded with greater or lesser significance) dependent on how congruously they integrate with an overarching life-narrative and with the goals of the self.

Thorne, Mclean and Lawrence (2004) conducted research into the self-defining memories of late adolescents. They found that meaning making was most linked to memories that expressed some form of tension or conflict, especially those memories that included themes of mortality or relationship. They consider this as *stress-related growth*. They also found that the memories that participants related to them as 'self-defining' contained a cluster of similar plot trajectories that included relationship beginnings and endings and family disruption and illness.

Finally, they described two qualitatively different categories of meaning making memories; the first category held '*lesson-learning memories*', this category related to

memories from which participants drew practical inferences that would direct future experience. The second category of memories they labelled '*gaining-insight memories*'. Memories in this category invoked meaning making of a deeper level. In *gaining insight* the individual made wider links between the messages gained from the specific experience and a developing sense of deeper self-understanding or knowledge about the world.

Conway and Holmes (2004) have linked autobiographical memory recall in elderly participants to Erikson's theory of psychosocial development. They elicited memories from elderly participants relating to significant meaning making crises in each decade of their life. Thematic analysis of the texts found that these memories related to each of Erikson's psychosocial stages of trust, autonomy, initiative, competence, self-definition, intimacy, generativity, and integrity. Narrative approaches, therefore, can be seen to preserve Erikson's premise that identity emerges through the individual's struggle to make sense of their self in a complex social world.

#### *Narratives of Contamination and Redemption*

Bluck and Glück (2004) asked individuals from a cross section of the life span (including adolescents, early adults and older adults) to define moments from their life story that they considered to be 'touchstones of wisdom'. They found that 'wisdom narratives' tended to expand across larger temporal periods and linked sets of related events together rather than focussing on isolated incidents. They also found that 'wisdom narratives' tended to concern negative or challenging situations

that led to an uplifting resolution or life-lesson. This is congruent with the work of McAdams, Reynolds, Lewis, Pattern and Bowman (2001) that looked at *redemption* and *contamination* narrative sequences in an individual's life story.

In redemption sequences the 'storyteller' constructs a narrative that depicts a transformation from an affectively negative life scene to an affectively positive life scene. In this narrative the negative life events are redeemed or made better as a result of wisdom or perceived benefits that result from the initially negative situation. A contamination sequence involves the reverse; a scene of positive affect is contaminated or ruined by the events that transpire in the narrative. McAdam's et al (2001) found that measures of psychological well-being were positively correlated with participants more inclined to generate redemption narratives and they related this to the literature on 'benefit-finding' (which is a type of meaning making) that occurs in adverse situations.

#### *Concluding Thoughts on the Application of Narrative Psychology to Living*

Narrative psychology considers the impact of biological and cognitive changes, the effects of role demands of particular life stages, and the impact of historical, cultural and cohort influences (Singer 2004). Narrative construction permits individuals to define themselves as unique persons, situated in time, with a consistent, continuous-self in the driving seat of their narrative journey as well as being social creatures who are multiply defined by life-stage, gender, ethnicity, class, sexuality, religion and culture (Singer, 2004). Singer puts it thus:

“The progressive momentum is from story making to meaning making to wisdom accumulation that provides individuals with a surer and more graceful footing on life’s path.” (Singer, 2004, p. 446)

The evidence suggests that themes of mortality, themes of beginnings and endings (particularly the beginnings and endings of relationships), and themes of family disruption and illness are particularly pertinent in generating meaning making. In view of this, Niemeyer (Niemeyer, 2001, 2004; Niemeyer, Prigerson, & Davies, 2002) has looked at the phenomena of post-traumatic growth and the process of narrative reconstruction following bereavement. He considers how survivors (re)create meaning following narrative crises caused by the loss of a significant other. But what of those who are dying themselves?

Research suggests (Bluck & Gluck, 2004; McAdams, et al., 2001) that when meaning making occurs in the face of challenge and distress, psychological well-being can be maintained or restored by either deriving wisdom through stress-related growth or benefit-finding from the experiences. Are such ‘redemption narratives’, as described by McAdams et al. (2001), possible in individuals facing death?

Having established the foundations of the narrative approach, this review shall now consider the literature that relates to the challenge of constructing a meaningful narrative to live by when faced with death.

### Meaning Making at the End of Life: Narratives of the Dying

In the early research that Saunders (1962) conducted in her journey toward developing the modern hospice movement, she witnessed in her patients the drive toward imbuing experience with meaning. Specifically she observed that individuals will actively seek to find meaning amidst the ‘total pain’ of dying. Giving time and space to patients’ stories is therefore a tradition entrenched in the history of hospice and palliative care (Bingley, Thomas, Brown, Reeve, & Payne, 2008).

#### *Narrative Disruption and Narrative Reconstruction*

As has been established, narratives are dynamic, ever evolving entities. Typically a narrative continues to develop gradually, broadening to accommodate new experiences, relationships and roles that the ‘author’ encounters. Over time it is likely that revisions to existing interpretations of autobiographical memories will occur due to the advancing sophistication, experience and cognitive development of the author (Singer, 2004). Revisions will also seek to maintain a reasonable consistency of ‘sense of self’ across time (Gallagher, 2003). That is to say: reinterpretation of past stories continues throughout life, contributing to meaning making and continuously, although usually modestly, reshaping the landscape of an individual’s biography (Frank, 1995; McAdams, 1994).

However, life clearly does not always move forward incrementally. Significant life events, which threaten the integrity of the ‘plot’ of the broad life narrative, can have

a very dramatic effect upon coping and narrative identity. For example, significant changes in role, in health or the loss of a significant other can have devastating effects upon the cohesion of an existing narrative (Bury, 2001; McAdams, 1993; Neimeyer, 2001).

Any of these changes can alter the genre of the story (from romance to tragedy perhaps), they may make previous narrative themes moot (themes of generativity may feel meaningless after the loss of a child), and they may alter the expected destination of the story (the future that was anticipated may seem obsolete following the loss of a partner). Neimeyer (2004) refers to these events as being ‘seismic’ in nature, fracturing the existing narrative and causing a crisis in narrative identity, which can only be restored to health through a narrative process of revision, repair or replacement of the basic thematic assumptions and goals.

This narrative process of repair involves reconstructing the narrative (Neimeyer, 2001; Pals, 2006; Williams, 1984). This reconstruction may involve changes as to which features of the stories are most highly attended to (i.e. new details are selectively added or enhanced in the narration while others are played down). Alongside this, perhaps more significantly, the meaning that various components of the story hold for the teller may shift over successive retellings.

These retellings occur both internally within the individual, being rehearsed without an audience, and also externally, engaging a listener who will contribute to the reconstruction process. The retellings have the effect of imbuing new meaning into the retold narrative, the consequence being that cohesion is restored (Williams,

1984). As previously noted, one further aspect of this meaning making process may involve the narrative action of 'benefit-finding'. This involves developing a sense that some gains were accrued from the distressing life event, perhaps in the development of wisdom or self, which may have created a more robust, sophisticated world view (McAdams, et al., 2001).

### *Illness as Narrative Disruption*

Illness constitutes a major instance of biographical disruption in which the relations between the body, the mind, and the ongoing experience of everyday life are significantly threatened (Bury, 1982, 2001). Individuals confronting disease, especially those with a terminal diagnosis, face particular challenges to narrative cohesion. One such issue is that of temporality, as Frank elaborates:

"The conventional expectation of any narrative is for [it to describe] a past that leads into a present that sets in place a foreseeable future. The illness story [presents a crisis] because its present is not what the past was supposed to lead to, and the future is scarcely thinkable." (Frank, 1995, p. 55).

### *Illness Narratives*

An illness narrative is the construction of a story that gives meaning to the experience of disease. The illness narrative shapes how the disease is perceived, enacted, and responded to by the 'self' and by others (Kohler-Riessman, 2004). The

illness narrative can be seen as including the psychological, social and cultural aspects of experiencing disease that are not included in the biomedical narrative.

The autobiography of Anatole Broyard, a literary critic for the New York Times, was published shortly after his death from prostate cancer. He composed his autobiography having learned that his illness was terminal. In it he writes: “it may not be dying we fear so much, but the diminished self.” (Broyard, 1992, p. 23) Jackie Stacey (1997), in her feminist *cultural study of cancer*, written following her own diagnosis of cancer, concludes that the fundamental purpose of the illness narrative is a continued (re)construction of self aimed at maintaining or renewing a sense of continuity of self in the face of death . Frank (1995) advocates that an essential value of the illness narrative is to permit the individual to be witness to their own narrative, allowing them room to make sense of their own reactions and to consider their own relationship to their illness, their body and their dying.

The German philosopher and literary critic Walter Benjamin writes: “a man’s real life... first assumes transmissible form at the moment of his death” (Benjamin, 1968, p. 94) In her article ‘the death of the narrator’, Belling (2004) interprets Benjamin’s words to mean that an unusual virtue of the dying individual, situated as they are at the end of life, is the capacity to knowingly construct an (almost) complete biographical narrative.

*The Content of the Dying Individual's Narrative*

In a paper entitled '*Making sense of dying*', Bingley, et al. (2006) analysed a wide variety of narratives written by authors who knew they were dying. To acquire their sample of narrative texts they conducted a bibliographic search of libraries, archives, journals and Internet sources. They were seeking English-written narratives that included books, poems, newspapers, journal articles, diaries and Internet postings, all published since 1950. 63 narratives were selected for content analysis by the authors. This sample size seems relatively modest given the potentially high volume of writings that must have been written over the 56-year period. This was perhaps a logistical necessity but suggests caution in generalising the findings of their analysis.

Their resulting observations show consistency with this author's experience of reviewing the literature concerning narratives of dying. The research highlighted four recurrent themes in the literature and a further four subthemes. It may be that these eight themes represent the experiences of disease that require the most narrative 'work' in an individual's process of meaning making. Here the notion of narrative 'work' refers to the telling and retelling of the story in an attempt to assimilate it into a cohesive story with a useful meaning.

The four main recurrent themes described by Bingley et al. (2006) were:

- The moment of diagnosis
- The story of subsequent treatment and sufferings
- The experience of medical interaction

- The self as an individual; with an independent life and relationships when outside the world of medical interaction

It is interesting to note that not only does this fourth theme connect to the ‘continuation of self’ goal of narrative, discussed in depth above, but it also touches upon McAdam’s (1990) assertion that an ongoing theme of narrative, across the lifespan, involves the development of a balance between autonomy/agency and relationship/communion. In individuals who are ill and dying this narrative theme must be extremely potent and clearly bears upon the ongoing negotiation of a narrative identity; people often define themselves based on their independence, competence and relationships with others.

The four subthemes identified by Bingley et al (2006) identified discussions about a narrator’s:

- Individual approach to illness and facing death
- Changing body image and loss of sexual function
- Changing relationship with family, friends, and working life
- Search for cures through alternative or complementary therapies

It is to the first of these subthemes, which highlights a person’s ‘*individual approach to illness and facing death*’, that this review now turns.

*Types of Narrative at the End of Life*

Drawing on a combination of his personal experience with disease and bereavement and many clinical interviews with the dying and chronically ill, the sociologist Arthur Frank (Frank, 1993, 1995) distinguishes between 3 types of narrative that may be present in the face of a significant life-limiting illness. These are restitution narratives, chaos narratives and quest narratives. Frank suggests that over the trajectory of an illness all three narrative types are likely to present at one time or another, alternatively and repeatedly.

*Restitution Narratives*

The restitution narrative frames the plot in terms of a journey that began in health, has now encountered ill health and is heading towards restoration of the healthy status. It is most often encountered in (and by) the recently ill, but it can be witnessed in the attitudes of sufferers, their families and often the health professionals providing them care (Frank, 1993, 1995).

The restitution narrative inevitably reflects the individual's desire to survive. Bury (2001) suggests that it is a learnt form of narrative. Examples of this narrative can be seen in Western medical institutions and in the attitudes of pharmaceutical companies, both of whom repeatedly convey the message that perfect health is ideal, should always be the priority of any intervention, and is almost always (re)attainable.

In the case of individuals who are dying, restitution narratives are, ultimately, likely to be insufficient to facilitate the explicit ‘awareness’ and insight that both Clark (2002) and the previously cited Age Concern (1999) publication have identified as integral to a ‘good death.’ As Roberts (1999) notes, “when stories fail, individuals struggle to live by stories that cannot adequately sustain them.” (Roberts, 1999, p. 22)

### *Chaos Narratives*

Chaos narratives lack the typical key features that define a narrative, as identified by Denzin (1989), above. Chaos stories are non-sequential, lacking discernable causality and plot, appearing as reactionary accounts of moment-to-moment life and lacking thematic structure, reflection, meaning making, or reference to identity based meta-narratives.

A chaos narrative is, effectively, a story *without* narrative plot. The features of the chaos narrative are equivalent to the narrative damage that Neimeyer (2001) describes following bereavement, a time at which pre-existing narratives have often become insufficient to imbue present events with useful meaning and coherence. However, in the chaos narrative the individual has not begun any process of reconstructing their damaged narrative.

The previously discussed review of dying individuals’ narratives of the past 50 years, conducted by Bingley et al. (2006), found retrospective descriptions of narrative chaos in individuals who had now restored some order to their narratives. Bingley et

al. (2006) found that narrative chaos was most often induced either at the moment of diagnosis, during unpleasant treatments or at the moment that the disease was declared terminal. One of the written narratives that they analysed described this moment as “the moment of the abyss opening.” The writer Michael Gearin-Tosh (2002) relates his own experience of the news that he had a terminal cancer, stating: “the news of a lethal cancer takes you over.”

As restitution narratives are ultimately going to fail and chaos narratives represent a form of distressing narrative dysfunction, the question arises as to whether there exists an adaptive approach to narrative.

### *Quest Narratives*

As Bingley et al. (2006) note in their review, the quest of which Frank writes represents a search for meaning and an aspiration towards acceptance of mortality. This narrative, which may take a religious or a philosophical path, ultimately strives toward the acquisition of a meaningful life lesson that is transmittable to others. The concept of the quest narrative is in line with, and draws upon, the literature on benefit-finding (Helgeson, Reynolds, & Tomich, 2006; Lechner, et al., 2003; Tomich & Helgeson, 2004), stress-related growth (Park, 1998; Tedeschi, Park, & Calhoun, 1998) and redemption narratives (McAdams, et al., 2001).

Communicating the meaningful lessons that are derived from the experience of dying takes the form of a narrative presentation. So narrative processes are used both to draw the meaning *from* experience and then to express the meaning *to* others. This

expression of the narrative gives it its purpose; having another person bear witness to the journey (or at least bear witness to the narrative of the journey) appears to give the journey its value (Bingley, et al., 2008; Frank, 1993; Madden, 1993).

It is interesting to consider the differences in coping of individuals demonstrating different narrative types. McAdams et al. (2001) did just this when they posed the question: are styles of narration (contamination and redemption) correlated with measures of life-satisfaction, self-esteem, and depression? Their study explored the connections between the psychosocially constructed autobiographical self and the psychosocially experienced quality of life and found that a redemptive style, when present in the life story accounts of the 70 adults interviewed, did in fact appear to correlate with higher levels of life satisfaction, higher self esteem and lower levels of depression.

When a person develops a terminal illness the story is usually of a healthy person whose life has been compromised by disease meaning that the type of narrative evident in the dying person's account of life could easily present as a contamination narrative. These ideas may be integrated with Frank's (1995) 3 types of narrative. The restitution form of narrative can be seen to seek hope through a belief that repair is possible, the contamination is therefore wished away by constructing narratives that deny it. The chaos narrative gives in to the contamination and falls apart. The quest narrative, however, seems intent on turning the contamination narrative into a redemption narrative, ready to be transmitted to an audience who may be prepared to validate and treasure it, thereby giving meaning, benefit and purpose to life even in the face of death.

### The Dying Body as Narrative Text at the End of Life

Inevitably there are many obstacles to be faced in the development of a satisfying quest/redemption narrative. Perhaps the greatest of these challenges is the impact of the degenerating physical body upon a sense of narrative identity.

Harold Brodkey, a Jewish-American author, wrote about his own experience of dying of AIDS in a series of essays published in the book '*The Wild Darkness: The Story of My Death*'. In the book he writes about his inability to have an identity in the face of death and comments: "It is curious... how my memories no longer apply to the body in which my words are formed" (Brodkey, 1996, p. 179)

Here Brodkey highlights the discontinuity between 'the narrative self' and 'the lived body'. These two aspects of human experience are put into conflict because narrative identity is built upon autobiographical memories in which the body is whole and undamaged. These memories of self are now at odds with the physical and dying body of the narrator (Belling, 2004). It can be seen from this one example that the impact of the dying body upon the dying individual's attempts at narrative reconstruction may be profound. It is to an exploration of the impact of the dying body upon narrative identity, upon the narratives that are told, and upon the manner in which these narratives are told that this review now turns.

Ultimately, it is the body, disrupted by disease, that drives the need for new organising narratives (Frank, 1995). The body is simultaneously cause, topic and

instrument of the new narrative that is generated in an effort to maintain the integrity of the self.

The author Jean Améry writes of his sense that his body, self and fate were entwined during his experiences as a Jewish detainee in a Nazi concentration camp:

“I had grasped well that there are situations in life where our body is our entire self and our fate. I was in my body and nothing else... My body was my calamity. My body was my physical and metaphysical dignity.” (Améry, 1980, p. 91)

What is striking in this account is the way that Améry’s words touch upon the notion of embodiment, with the body experienced as the foundational aspect of his existence. This gives the reader a sense of how dramatic an impact this embodied state (of distress and physical suffering) may have upon the narrative and meaning making processes of any individual.

### *Embodiment*

A pivotal position to consider when reviewing the impact of the body upon the construction of narratives is that of embodiment (also referred to, variously, as embodied cognition or the embodied mind position).

Philosophers (Clark, 2004), cognitive scientists (Lakoff & Johnson, 1999), neuroscientists (Edelman, 2006), and artificial intelligence researchers (Biocca, 1997) who hold this position attest that all aspects of the mind, and of mental life

generally, reflect the nature of the mind as an object that is interwoven with, and arises from, a biophysical body. The mind is thereby seen as shaped by the nature of its biophysical existence. This position is in opposition to Cartesian Dualism.

### *The Importance of the Body in Embodiment*

The body is the junction at which all human experience registers and where various forms of human experience interact (Kirmayer, 1992; Lakoff & Johnson, 1999).

An ‘experience’ may be an internal mental event, perhaps a thought that leads to an emotion, which in turn is registered as a physical sensation in the body. Alternatively the experience may be an internal physical event, perhaps a symptom of disease (a pain) or a natural change in the body’s state brought on by the circadian rhythm (sleepiness). The experience may originate as an external event, perhaps a physical knock (causing pain or surprise) or the chill of a cool breeze (causing a sense of cold or discomfort) or a tense social interaction with another person (causing anxiety, frustration, tense muscles, or sweaty hands).

All of these aspects of experience (cognitive, social, physical, emotional, environmental) interact in complex ways. This is the obvious tenet of much psychological theory. The point of this description is to highlight the powerful ways in which these complex interactions of experience are intrinsically tied into the body as the primary location of *lived experience*.

If the body is considered the primary location at which an individual encounters and deconstructs all modes of experience and within which reactions to the world are generated (i.e. the person is seen as an embodied agent within the world), then this has implications for the manner by which meaning making and narrative construction occurs. These ideas derive from the work of Merleau-Ponty (1962) and his considerations of the phenomenology of perception.

### *Metaphors of the Body*

In their book '*Philosophy in the Flesh*', Lakoff and Johnson (1999) argue that a prominent feature of (embodied) human thought is the generation of frequent body-related metaphors. As in the narrative and constructivist positions, perceiving reality is not seen as a consequence of directly sampling the world objectively and knowing it as it *is*, but instead is seen as arising out of a process of relating to the world through metaphors that are drawn from an individual's experience of having a body.

An individual's experience of having a body is essentially their first experience. Attachment theory (Ainsworth, 1978; Bowlby, 1969; Fonagy, 2002; Mesulam, 1998) demonstrates that dyadic-relational experiences that occur between an infant and a primary care giver regulate (or fail to regulate) the bodily-felt emotional processes of the infant. These bodily-felt experiences, occurring in a social context, drive the development of emotion regulation, social awareness, and a sense of self and identity. Lakoff and Johnson (1980) advocate that from these elemental body-centered experiences more complex conceptions (or schemas) of the world and of an individual's sense of self-and-other are developed, all underpinned by a body-based

metaphor-orientated construction of experience. Lakoff and Johnson (1980, 1999) cite their extensive linguistic analysis to support their claims of the importance of the body in the metaphors people routinely use to communicate a wealth of experience. A few brief examples, to give a flavour of their meaning, include statements such as: 'I grasped the idea', 'the idea went right over my head', 'I was touched by his remark', 'it was a shoulder to cry on', 'this marriage is dead', 'this marriage is strong', 'he was back on his feet in no time', 'he was getting on my nerves.'

Lakoff and Johnson (1999) come to the bold conclusion that: "the very structure of reason itself comes from the details of our embodiment" (Lakoff & Johnson, 1999, p. 4). However, see Goschler and Darmstadt (2005) for a critique of the conclusions that Lakoff and Johnson reach.

Kirmayer (1992), in his paper exploring '*the body's insistence on meaning*', discusses this same proposition, advocating that experience is often organised based on the metaphoric similarities between the meanings attributed to experiences and appropriate descriptive sensorimotor equivalences (Kirmayer, 1992). In support of this Winner (1988) has demonstrated that adults can understand and process metaphors as quickly as literal information. Kirmayer (1992) believes that the effect of using body-related-metaphors is to make descriptions of the world seem immediate and visceral.

In integrating the use of language, and the impact of that language upon effective social communication, with bodily experience Kirmayer (1992) is tying together two of the essential components of narrative based meaning making processes (identified

above), those being language processes and the effects of social interaction/performance, with the lived body-orientated way in which individuals encounter their worlds. This contributes toward an understanding of how individuals draw meaning from their illness experiences by elucidating the importance of the body state upon factors such as cognitive organisation of information about the world, use of language and social communication.

### *Multiple Bodies*

The discussion above has highlighted the role of the body as a vessel of lived experience. However, the body is also an object, situated in the world, which is owned by the self, shaped by cultural expectations and used purposefully to perform actions and to perform socially. This second conception of the body, as 'a behaving, culturally inscribed body', was first delineated by Foucault (1975). Crossley (1996) acknowledges these two conceptions of the body, both the lived (Merleau-Ponty, 1962) and the inscribed (Foucault, 1975), and argues for the importance of retaining the insights permitted by maintaining a separate awareness of these two forms of the body.

Illness, and the profound experience of living in a dying body, therefore has an impact on the body as lived (and as experiencing entity), the body as performing agent (capable/incapable of independence and engaging in social interaction), and, also, the body as symbol (and, perhaps, as symbolic of the self). The body as symbol relates to the popular conception of body image. With these multiple types of body in mind, changes may be seen to occur in the very way that the body encounters and

processes experience, in the capacity of the body to perform, in the cultural expectations which affect societies perception of the body and which shape the behaviour of the owner of the body, and in the value of the body as object as perceived by the body's owner and by others.

How, then, might the failing cohesion of these multiple human bodies impact upon the cohesion of an individual's narrative?

### *The Unbounded Body*

A bounded body here refers to a whole, undamaged body in keeping with the Western construction of the person as residing in a stable, bounded and autonomous entity, while the unbounded body may be seen as compromised and unstable and in more extreme circumstances of disease may be seen as disintegrating (Lawton, 1998).

In her book 'Cancer in Two Voices', Barbara Rosenblum discusses her experience of living with terminal breast cancer. She observes that her body "no longer contains the old truths about the world" (Butler & Rosenblum, 1991, p. 165). Similarly, Kirmayer's (1992) discussion of embodied experience argues that "injury or alteration of the body changes not only the content of thought, but also its form." (Kirmayer, 1992, p. 336). Merleau-Ponty (1962), Foucault (1975), Lakoff and Johnson (1980; 1999), Frank (1993; 19995), Brodkey (1996), Amery (1980), and a great many of the authors analysed by Bingley et al. (2006) would all likely recognise the import of both of these observations.

Further support of this may be found in a study conducted by Lawton (1998).

Lawton (1998) conducted a 10-month participation study in a hospice in southern England. During this time she interacted with, and made observations of, some 280 inpatients, as well as observing and interacting with nursing staff. She also carried out one in-depth case study of a patient. Lawton (1998) argues in her paper that a significant proportion of the patients that she observed were admitted to the hospice because their disease caused violations of the body's conventional boundaries, for example they were experiencing ruptures of the body, which often included bodily emissions of fluids or matter normally contained within the body.

It is interesting to note that Lawton (1998) recorded some of the body-based-metaphors that she observed nursing staff using when describing patients who showed the most significant levels of bodily degeneration. These included metaphors such as "falling apart at the seams" or "being eaten away by their cancer". These metaphors depict the loss of cohesion that was occurring and echo Lakoff and Johnson's (1999) observations concerning the prevalence of embodied metaphor in people's constructions of experience. This raises questions about how an individual with an unbounded body experiences the world if, as Lakoff and Johnson espouse, a major organising principle of experience is embodied metaphor. Does the breakdown of the body therefore lead to a breakdown in the coherence of the perceived world of the dying individual?

Lawton (1998) observed that patients who were experiencing a profound degeneration of their body showed acute social withdrawal and dissociation. She argues that the breakdown of the body's boundaries significantly undermined the individual's sense of self and social identity (Lawton, 1998).

Copp (1997) also conducted a study that considers the impact of the body's boundedness upon the dying person's sense of self. This qualitative investigation of the experiences of 12 individuals dying in a hospice included interviews with dying patients and the nurses caring for each of the dying patients. Copp (1997) found that the closer a patient got to death the more the patient and the nurse were likely to make references that suggested that the 'self' and the 'body' were separate. Interestingly Martin (2001) describes a similar temporary fragmentation of the self in women experiencing difficult births. In these cases of difficult childbirth the body was spoken about as if it was other than self, i.e. as an externalised, separate object.

Lawton (1998) acknowledges Martin's data observing that what is significant in the instances described by Martin (2001) is that whilst the self becomes dissociated from the body, it continues to exist as a self. However in the most irreversibly 'unbounded' hospice patients that she observed Lawton (1998) felt that the self appeared to be absent "leaving little, if anything, but the empty body" (Lawton, 1998, p. 130). Copp's (1997) data seems to suggest that dying individuals (and the nurses caring for them) do indeed begin to distance the 'self' from the body as death nears, while Lawton's observations suggest that at a certain threshold of unboundedness (that is, of bodily degeneration) the self may be lost entirely.

Lawton (1998) therefore concludes that identity and selfhood is fundamentally dependent upon the possession of a physically bounded body. It is uncertain from Lawton's study exactly how the failing cohesion of the body causes the diminishment of the self. Certainly the trauma of such events must have a significant impact upon an ability to remain engaged in interpersonal and intrapersonal processes, as must the very state of the body which houses the mind and its capacity to interact and reflect.

Drawing on Foucault (1975), Merleau-Ponty (1962), Frank (1993; 1995), and Lakoff and Johnson (1980; 1999) it is possible to frame this in narrative terms:

The body as lived, the body as inscribed, and the body as object owned by the individual, all play a central role in the construction, performance, coherence and cohesion of narrative identity. Loss in the body's cohesion may severely undermine the individual's sense of continuity, their patterns of social interaction and their personal identity. However, while an individual's narrative identity may be at threat from the body's degeneration, it may be that a protective process occurs, a process generated by building a redemption narrative amidst the suffering that may allow a sense of purpose and a sense of value in the suffering to be maintained. A narrative framing of these experiences also underscores the importance of creating space for the narrative to be shared and transmitted so that it can be held by others when the individual has lost the cohesion to hold it themselves.

### Does Everybody have a Story in the Making?

A critical issue not explored in the current literature pertains to the extent to which narrative is universally employed as an adaptive process. It may be that there are people who simply do not want to talk about their experiences for a number of reasons, including the possibility that their life has been populated by traumatic and uncontrolled events (e.g. Holocaust survivors; people who have been in serious accidents; people who have had multiple losses; survivors of terrorist attacks). These people may survive as a direct consequence of *not* telling their stories, and choosing instead to focus on present and/or future aspects of their lives.

The challenge for the researcher in the domain of narrative studies is to try and determine to what extent one can extrapolate from relatively limited findings into the general population. By definition individuals who write about their own narrative journeys, or the participants who volunteer for studies exploring narrative processes, are a self selected group, possibly because they find an intuitive appeal in telling their story.

If there are indeed people who decline or do not think about understanding their narrative, it would be interesting to explore the potential or actual consequences of this on identity and quality of life. Further research needs to be undertaken to explore these issues.

## Conclusion

The discussion in this literature review has been developed from ideas brought together from a variety of constructivist and narrative domains and has in large part been developed from the academic and literary narratives created and published by a relatively small set of lay-persons, scholars and academics who have endured their own illness and dying. This is a reflection of the relative infancy of formal research in this area. The theory and ideas described and developed in this review very much represents a work in progress in an area where methodical and methodologically sound research is required to detail more broadly the effects that a life-limiting diagnosis has upon an individual's meaning making processes.

The World Health Organisation concluded in their 2004 report that it is essential to generate new research that pays particular attention to the social, psychological and spiritual aspects of palliative care. (World Health Organisation, 2004, p. 28).

Developing further evidence-based knowledge of the experiences and psychosocial processes of the dying is essential to advance the quality of care at the end of life.

Approaching this need for new research from a narrative paradigm, which seeks to analyse the multiple texts created by and about dying individuals (e.g. the stories the dying tell, the stories that others tell of them, and the stories that society and culture tells of the dying), has a very natural fit with the nature of these experiences. That is to say: dying individuals may be seen, from limited evidence, to naturally generate narrative based processes of re-evaluating and reconstructing meanings, aspects of

identity, purpose, values and relationships and many other thematic structures which imbue and shape their life stories. It would therefore be in keeping with the narrative paradigm and the evidence of the preceding literature review to suggest that qualitative, interview based methodologies would be appropriate to begin recording, analysing and understanding the patterns of these meaning making processes.

This literature review has suggested one particular way into the potentially overwhelming scope of exploring meaning making at the end of life, namely in considering the role of the body, multiply defined as it is, in shaping the narratives that are produced at the end of life. Further research may, therefore, seek to explore the changing nature of an individual's relationship with their body following a life-limiting diagnosis.

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## **Empirical Paper**

# **An Exploration of the Effect of a Life-limiting Diagnosis on an Individual's Relationship with their Body: A Qualitative Study**

*Running head:* Relationship to the-body-with-disease

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This paper was written as if for publication in Qualitative Research in Psychology<sup>1</sup>

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<sup>1</sup> See Appendix B for the guidelines on author submissions to Qualitative Research in Psychology

## ABSTRACT

To date, there is little research into the lived experiences of individuals with a life-limiting diagnosis. This current study utilises a qualitative methodology to address this by investigating the effects of a life limiting diagnosis on an individual's relationship with their body. The construct of 'relationship to the body' was identified through the clinical experiences of psychologists working within the palliative care domain and was felt to be a strong route into investigating the ways in which individuals with a life-limiting diagnosis ascribe meaning to their experiences.

11 participants were interviewed about their relationship with their body. Interviews were transcribed verbatim and analysed using Interpretive Phenomenological Analysis. Eight over-arching themes were identified, along with 24 higher-order themes.

Themes that emerged from the data included: the experience of the changed body, fear of the body's future, threats to the individual's sense of ownership of the body within the context of the medical encounter, and adaptivity to disease.

Discussion of these constructs focussed on the experience of embodiment that can be seen to underlie participant's lived experience of disease.

## INTRODUCTION

To date, there is a clear paucity of research into the lived experiences of individuals with a life-limiting diagnosis (Yedidia & MacGregor, 2001).

The literature that does exist is largely non-evidence based<sup>2</sup> and has been authored by both laypersons and academics who have written narrative accounts of their own experiences of illness, disease and dying (Bingley, et al., 2006). This body of literature sits within a narrative-based constructivist epistemology, a perspective that assumes that people construct their own realities through a combination of interpersonal and intrapersonal processes (Raskin, 2002). These processes, also referred to as 'meaning making', function to create a sense of the world as meaningful and coherent. Narrative psychologists advocate that meaning making is achieved by applying narrative structure to the organisation of experience and through the development of a strong autobiographical account of the self (McAdams, 1987; Neimeyer, 2001).

Developing evidence-based knowledge about how individuals living with a life-limiting diagnosis apply meaning making processes to their experience is essential in order to incorporate a richer description of the lived-experience of illness and dying into ongoing efforts to improve end of life care. The aim of this research is to contribute to that end.

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<sup>2</sup> Although see Benzein, Norberg and Saveman (2001), for a qualitative exploration of the meaning of the lived experience of hope in palliative care.

## Developing the Research Focus

The focus for this research was developed in two stages.

Initially it arose as an interest of the author due to the author's previous clinical experience of working therapeutically with individuals with a life-limiting diagnosis. During this work the author found that clients' efforts to make sense of the profound experience of living with a degenerative disease were often at the forefront of the therapeutic work and the 'success' by which this process of 'meaning making' occurred seemed to have a significant effect on the levels of distress experienced by the client. Over time, and guided by an experienced clinical supervisor, the author began to notice recurrent themes in the meaning making narratives of the clients. These included fears about dying and death, the nature of their changing social roles, the purpose and value of their lives and their changing relationship with their body as a result of the disease.

The significance of these recurrent themes was echoed in the experience that the author's clinical supervisor brought into supervision and also in wider discussions with other experienced Clinical Psychologists who worked in the Palliative field at that time, (encountered primarily through the professional Palliative Care Special Interest Group.)

In devising this research each of these themes were considered as part of the process of identifying key constructs that were likely to be generating an active process of meaning making in the dying individual.

In the second stage of developing the research focus, an awareness of these themes was carried forward into a comprehensive review of the literature on meaning making in individuals with a life-limiting diagnosis. This involved reviewing many texts that explored the process of generating narratives that could sustain a sense of meaning and purpose in life whilst living with such a diagnosis. It was clear that the theme of the 'changed body' was often evident in the literature, forming an integral construct around which meaning was constructed and through which an individual's experience of the world began to change as a consequence of the disease's progressive impact upon the body. However, there appears to be no direct, empirical research on the lived experience of an individual's changing relationship with their body.

Exploring this theme therefore represented a strong route into exploring a part of the wider process of meaning making at the end of life.

#### Existing Research Pertaining to the Effect of a Life-Limiting Diagnosis on an Individual's Relationship to their Body

While there has been no direct research exploring the broad, lived experience of the effects of a life limiting diagnosis on an individual's relationship with their body,

there is a modest quantity of research describing some aspects of the experience of the body with disease.

Cort, Monroe and Oliviere (2004) discuss the implications of a diagnosis of terminal cancer on the sexual relationships of couples and underscore the impact that a drastically altered body image and altered bodily functions may have upon the individual and their capacity and confidence to engage in sexual activity. They draw attention to a number of disease-related aspects of bodily experience likely to impact upon an individual's sexuality, which include an increased sense of vulnerability, a sense of helplessness possibly connected to a loss of control of some bodily functions, potential feelings of distaste at their own body and a related abnormality in body image, anxieties about pain and the body's degeneration, feelings of guilt and burden, self blame for the possibility of having caused or contributed to the illness, and anger and resentment that they have a terminal disease. They note that pain, nausea, vomiting, fatigue and constipation may all contribute to an altered experience of the body and preparedness to engage in sexual activity. These observations have a strong intuitive appeal and appear to be grounded in their clinical experience, but are not derived from empirical data.

In a study that comes closest to the nature of this present research, Hinsley and Hughes (2007) explored participants' lived experience of cachexia<sup>3</sup>. They interviewed 12 participants to explore the impact of cachexia on body image. They found that the participant's altered body image impacted upon their embodied experience of day to day life, their relationships and their social functioning, while

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<sup>3</sup> Cachexia is a common symptom of advanced cancer seen as a physical wasting of the body due to the multiple physical and metabolic effects of the disease.

also causing participants to live more restrictive, isolated lives. Most interestingly participants discussed their repeated attempts to re-adapt to disruptions of self caused by an altered body image, thereby demonstrating the active meaning making processes underlying the theoretical assumptions of this research.

Münstedt, Manthey, Sachsse, and Vahrson (1997) used a quantitative methodology to explore the impact of altered body image by analysing the impact of alopecia upon measures of body image. They achieved this by administering the Frankfurt self-concept scale and the Frankfurt body-concept scale at three intervals; before chemotherapy, at the point at which alopecia was complete, and after re-growth of hair. They found that 73.3% of the 29 participants experienced a significant drop in measures of self-concept and body confidence, which was maintained after re-growth of hair.

These studies both address the experience of an altered body image, which Price (Price, 1995, 2000) defines as:

“... a state of personal distress, defined by the patient, which indicates that the body no longer supports self-esteem and which is dysfunctional to individuals, limiting their social engagement with others” (Price, 2000, p. 180).

This current work differs in at least one significant respect from the studies of Hinsley and Hughes (2007) and Münstedt, Manthey, Sachsse, and Vahrson (1997), as they both explicitly focus on altered body image, whereas this research focuses on the broader concept of ‘relationship to the body,’ which may include multiple aspects

of the body as a construct, including the body ‘as lived’, the body as an object that performs functionally, the body as an inscribed-cultural object and finally, in common with these studies, the body as it relates to body image (or body ideal).

A study which does bear upon an individual’s relationship to their body beyond the scope of their changed body image was conducted by Enes (2003). She interviewed 8 palliative patients, exploring the impact of advanced illness on their experience of dignity and applying a thematic analysis methodology to indentify the components that made up the construct of dignity. Dignity in this context was found to be a complex phenomenon composed of four main dimensions; ‘being human’, ‘having control’, ‘relationships and belonging’ and ‘maintaining the individual self’. Of these four components, two of them related to the participants’ relationship with their bodies. ‘Having control’ related to both the power to make choices and the ability to control their bodies, particularly in the context of continence (i.e. actual or feared incontinence was frequently mentioned as significantly compromising a sense of dignity). The theme of ‘maintaining the individual self’ related to the state of the individual’s physical appearance and their ability to present their body (e.g. to dress themselves, to put make up on), as well as relating to the continued capacity to keep both emotional and physical aspects of their experience private. This component was strongly connected to the participants’ desire for continued independence.

Enes’ (2003) study did not set out to specifically consider the participants’ relationships with their body. Instead this theme arose from the data. In a similar vein Lawton (1998) conducted a ten month participant observation study at a hospice in the south of England, from which she drew conclusions that relate to the person-body

relationship. Specifically she concluded that in instances in which the physical ‘boundedness’<sup>4</sup> of an individual’s body has become significantly compromised by disease, then the individual is likely to display behaviours that indicate a loss of self and of social identity. Essentially her observation was that as the body broke down, so did the integrity of an individual’s personhood<sup>5</sup>. Copp (1997), however, found evidence that may challenge Lawton’s conclusions. In interviews with patients whose death was imminent, and with their nurses, she found that reference was often made to ‘the body’ as separate from ‘the self’. In Copp’s (1997) framing, as the body broke down the self was essentially extracted from the body through a narrative process of social discourse and meaning reconstruction and therefore remained intact.

It may strike the reader that this brief review of the existing research on an individual’s relationship with their body at the end of life jumps somewhat unevenly from one aspect of an individual’s experience with the lived body to another. This is a reflection of the current state of research in this area, which consists either of research into isolated aspects of people’s lived experience of the body with a terminal disease or of occasions where the relationship with the diseased body has arisen as a theme in a broader piece of research. To date this subject matter has not been directly approached with a methodology that seeks to explore the broad nature of the lived experience of the body-with-disease. The present study seeks to address

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<sup>4</sup> A bounded body refers to a whole, undamaged body in keeping with the Western construction of the person as residing in “a stable, bounded and autonomous entity” (Lawton, 1998, p. 134), while the unbounded body may be seen as disintegrating and lacking the corporeal capacity for self-containment.

<sup>5</sup> Perry and O’Connor define personhood “as associated with self esteem, the place of the individual in a social group, the performance of given roles, and the integrity, continuity and stability of the [person’s] sense of self” (Perry & O’Connor, 2002, p. 55)

this, employing a qualitative interpretive phenomenological methodology focussed on the person-body relationship that, as best as possible, seeks to approach the subject matter free from pre-existing assumptions.

## METHOD

### Methodological Approach

Interpretative Phenomenological Analysis (IPA) was selected as the most appropriate methodology given that the research sought to develop a rich account of the participant's lived experience of relating to their bodies in the context of their disease.

IPA seeks to explore in detail how participants make sense of their lived experiences. The IPA approach provides a method of analysing interview data which seeks to produce a comprehensive set of rigorously defined and structured themes that are drawn from, and sourced in, the data (Smith, Flowers, & Osborn, 1997; Smith & Osborn, 2003).

IPA assumes that participants reflect upon, interpret and organise their experiences, ultimately resulting in a meaningful construction of the experiences (Brocki & Wearden, 2006). The goal of the IPA researcher is to access and describe the participant's personal world of meaning whilst acknowledging that any description that arises from the data is dependent upon, and complicated by, the researcher's own conceptions of the world (Smith, 1996). The analysis is therefore interpretative

in that the researcher must make interpretations and engage in their own meaning making processes, and phenomenological in that it is rooted in the participants' experience of the subject matter (Eatough & Smith, 2008).

In retaining an awareness of the researcher's role in constructing the themes that emerge from the data, IPA can be said to hold a position of critical realism; it strives to describe the internal realities of the participants, rather than an objective reality, as best it can, while acknowledging the influence of the researcher's interpretation.

The existing literature on people's experience of living with a life-limiting disease is embedded within a constructivist paradigm that emphasises narrative and meaning making processes. This present research has arisen, in part, due the fact that the existing literature currently lacks a strong base of empirical research. IPA represents an empirical approach with a good fit to the subject matter because it sits authentically within the constructivist paradigm.

The data in this study are interview transcriptions from face-to-face semi-structured interviews with 11 participants. This method of collecting data was deemed appropriate because it allowed for a broad enquiry in to an area in which there is little pre-existing data and therefore no established theory or testable hypotheses. Further, the population that this research focuses upon, that is individuals with a life limiting diagnosis, represent a sensitive population whose experiences are likely to be complex and require sensitive handling. Face-to-face semi-structured interviews allowed for the rich complexity of their experiences to be recorded most fully and

also meant that the researcher was able to respond sensitively and appropriately to the salient emotional needs of the participants.

### Participants

Participants were recruited from specialist out-patient day centres that operate within a hospice in the southeast of England. The inclusion/exclusion criteria were kept to a minimum as the explicit approach to this research was to minimise preconceptions about the data that might be produced. As a result, any individual attending any of the outpatient day centres who was able to engage in a reflective verbal discussion of their experiences in English, had a life-limiting diagnosis, and was able to give informed consent was eligible to be invited to participate, regardless of their disease type, disease stage, gender, or age (although the minimum age for accessing the hospice's services is 18). Based on these criteria no attendees of the day centres were excluded from an invitation to participate in the research.

### Recruitment

#### *Approaching Participants*

The researcher spent time discussing with the management staff of the day centre the most appropriate way to approach potential recruits. It was essential to make sure that prospective participants felt no pressure to participate, it was also important that the invitation to participate in the study was delivered at an appropriate point within their 6 week program of attendance at the specialist day centre (i.e. not so early that

they felt overloaded with information, not so late that they couldn't access support through the day centre staff should they wish for support for any reason following the interview).

Each of the specialist day centres is run once per week for 6 consecutive weeks. It was agreed that the researcher would attend the centre to give a brief presentation on the nature of the research, distribute information sheets (see Appendix E) and be available to answer questions. This occurred on the 2<sup>nd</sup> session of each of the six intakes to the program that were approached. While questions were responded to as fully as possible, the discussions were always carefully bounded so that they did not open up into an unplanned group discussion of experiences relating to the body for which the day centre staff were not prepared.

### *Recruiting Participants*

Following the presentation of information to prospective participants the researcher invited them to 'opt in' to the study by informing a member of the day centre staff (who were unaffiliated with the study) that they wished to participate and returning a signed consent form (see Appendix F). Prospective participants were encouraged to spend time considering if they would like to participate and it was made clear that they could take as long as they wished to do this, choosing to 'opt in' at any time during the frame of the 6 month recruitment/data collection period.

### Ethical Considerations

Ethical approval to conduct the research was granted by the Southampton School of Psychology ethics committee, the Local NHS Research Ethics Committee (see Appendix C), and the hospice ethics committee (see Appendix D). Detailed consideration was given to the possibility of participant's experiencing distress (physical and/or emotional) in this sensitive population. Measures were taken to minimise this and follow up support was available to all participants. In accordance with the British Psychological Society Code of Conduct (British Psychological Society, 2006) participants were reminded that their data would be anonymised and that they had the right to withdraw at any time without the need to explain their decision.

### Planning the Sample Size

Guest, Bunce and Johnson (2006) systematically documented the degree of data saturation and variability during a study that involved thematically analysing sixty in-depth interviews with participants. They found that saturation had occurred within the first 12 interviews and that basic elements for all meta-themes were evident as early as interview six. Meanwhile Creswell (1998) makes a clear recommendation to interview at least 10 people in a phenomenological study. Based on this evidence and recommendations, this research aimed to recruit 12 participants and ultimately succeeded in conducting interviews with 11 participants.

### Sample Size and Characteristics

Approximately 50 – 60 people were invited to participate in the research (across six different day centre intakes) by means of a short presentation by the researcher. 15 people volunteered, one person then withdrew at the point at which the researcher attempted to arrange an interview and in three cases the health of the volunteer significantly declined before it was possible to arrange an interview. This left 11 participants who completed interviews. Participant details are presented in Table 1, below.

Table 1

*Participant details*

Participant Code	Gender	Age	Disease	Duration of Interview
1	Male	54	Prostate cancer	70 minutes
2	Male	70	Prostate cancer	65 minutes
3	Female	51	Motor Neuron Disease	60 minutes
4	Male	58	Bowel cancer	70 minutes
5	Female	58	Pancreatic cancer	45 minutes
6	Female	74	Breast cancer	40 minutes
7	Female	55	Breast cancer	45 minutes
8	Female	71	Breast cancer	40 minutes
9	Female	75	Bowel cancer	50 minutes
10	Male	59	Small cell lung	45 minutes
11	Female	43	Bowel cancer	75 minutes

As can be seen in Table 1, 4 men and 7 women participated, with an age range of 43 to 75 years (mean age 60.8 years). Participants had prostate cancer (2), Motor Neuron Disease (MND) (1), bowel cancer (3), pancreatic cancer (1), and small cell lung cancer (1). All participants were white British.

## Procedure

### *Developing and Applying the Interview Schedule*

A script was devised to be read at the start of the interview that reminded participants of their right to withdraw and let participants know what to expect from the interview (see Appendix G). The opening script concluded with the primary open-ended question of the interview: “To begin then: could you tell me about your relationship with your body?”

As per the philosophy of IPA, this first question is considered the most important and was the only one systematically asked in every interview. Following this the researcher used clinical skills to follow the lead of the interviewee, letting them set the direction of the conversation for the most part, yet attempting to ground the interview around a curiosity about the participant’s relationship with their body.

Often the interview moved on to other topics for a short time. Allowing this to occur was a conscious decision on the interviewer’s part, warranted by the fact that when a participant sets the interview in any particular direction it is not possible to be certain what content such a direction will generate and how that may ultimately prove relevant to the constructs created by the analysis.

The final question in every interview asked the participant if there was anything not covered in the interview that they felt was relevant to their relationship with their body. This meant that the topic of relationship to the body was not confined by the

interviewer's sense of what this meant. Participants were reminded that they were the experts in speaking about their relationship with their body.

Several other open-ended questions were devised to keep the interview flowing. The researcher and the research supervisors devised these questions by drawing upon their clinical experience, consulting with other palliative care professionals at the hospice, and from a review of the relevant literature. The questions are detailed in Figure 1 below.

- Tell me about your relationship with your body?
- Prompt if required: Has your relationship with your body changed?
- What was your relationship with your body like before your disease?
- I'm guessing that you get quite a lot of symptoms, what's that like for you?
- Sometimes people's feelings about their body, how it looks, how it feels, what it is capable of, have an impact on their sense of who they are, on their sense of identity, and on their confidence and self-esteem. Has the impact that the disease has had on your body had any effects like this for you? Please tell me about them.
- I imagine that you often have to, or want to, explain your experiences and symptoms to others (perhaps doctors and family members). How do you find the experience of doing this?
- Is there anything that we haven't spoken about, or that I haven't asked, that you would like to share with me about your relationship with your body?

*Figure 1:* Interview Schedule

*Details of the Interviews*

Interview duration ranged between 40 minutes and 75 minutes (mean interview duration was 55 minutes), see Table 1 above. The length of the interview was determined in negotiation with each participant based on their commitments that day, their comfort, and a sense that the interview had covered all the talking points of the subject matter for that particular participant. Toward the end of each interview the participant was asked if they wanted to add anything further on the subject to ensure that the interview had sufficiently covered all the information, views and reflections that the participant wished to share.

All interviews were digitally recorded. All interviews were conducted by the researcher/author.

**Analysis of the Data**

All the digital recordings were transcribed verbatim in their entirety by the researcher/author resulting in 107 pages of transcript. A number of additional descriptors were included in the interview, usually detailing the emotional presentation of the participants as indicated by vocal intonation.

Analysis of the interviews utilised the IPA procedure detailed by Smith (1996), Eatough and Smith (2008) and Smith and Osborn (2003).

Every transcript was read through a number of times, notes were made on specific content and then tentative interpretations of the text began to yield themes. This process was repeated on each interview transcript and common themes began to emerge. Over many successive readings these themes were refined and a process of grouping the themes into higher-order thematic clusters was started. Following this, the higher-order themes were organised into over-arching themes.

At this stage of the analysis every quote that supported a higher-order theme and an over-arching theme was ordered on to a table (Appendix I) to provide a detailed audit trail charting the process of interpretation from the verbatim transcription text up to the over-arching themes. Setting all the data out in the table brought a number of revisions; in some cases multiple higher-order themes were collapsed together while in other cases higher-order themes were moved to new over-arching categories as setting the quotes out in this way provided a clearer indication of their place in the overall structure. The audit trail that this table provided demonstrated the internal validity of the constructs.

### Quality Assurance

The table depicting the analysis was then presented to both of the research supervisors and two further Clinical Psychologists, each of whom examined the interpretations made of the quotes and followed the audit trail from these interpretations up to the overarching themes. A number of suggestions were made for revisions that tightened up the internal construct validity of each higher-order theme and over-arching theme. These steps are in keeping with guidelines on assuring

quality in qualitative research (Mays & Pope, 2000). See Appendix I for the final ordering of the data.

## RESULTS

Interpretive Phenomenological Analysis of the transcription data yielded eight overarching themes and twenty-six higher-order themes that described constructs relating to the participants' relationships with their bodies in the context of their life limiting diagnoses. All themes that emerged from the data are detailed in Table 2, below, which also depicts the frequency with which each theme was endorsed by the sample.

Table 2

*Emergent themes and the number of participants endorsing each theme*

Over-Arching Theme	Higher-Order Theme	N endorsing higher-order theme	N endorsing over-arching theme
The changed body	Frustration and distress at changes in the body's capacity to perform	4	
	Relationship with the body more explicit as a consequence of disease	6	8
	The lived body is no longer experienced as predictable	4	
Changes in self	The changed body as unrepresentative of self	5	
concept as a consequence of the changed body	Changes in social role (due to diminished physical capacity)	2	6

Over-Arching Theme	Higher-Order Theme	N endorsing higher-order theme	N endorsing over-arching theme
Fear of the body's future state	Fear of the physical experience of death (i.e. suffering at the end)	3	
	What next? General fear of the body's unknown future	3	6
	Anxiety/rumination about the meanings of recent/current bodily-sensatory-experiences	5	
Adaptation	Learning to listen to the body	4	
	Adapting plans & planning in advance	2	5
	Gaining satisfaction from adaptive goals	2	

Over-Arching Theme	Higher-Order Theme	N endorsing higher-order theme	N endorsing over-arching theme
A Tug of War: Ownership of the body	Losing private ownership of the body: Threats to the privacy and boundaries of the body		
	Who knows best?		
	Compromising informed choice and ownership of the body	4	9
	Retaining ownership of the body (includes making choices about treatment and challenging medics)	4	
	Sharing the body's space	3	
	Empowering self through self-education & research	4	

Over-Arching Theme	Higher-Order Theme	N endorsing higher-order theme	N endorsing over-arching theme
Communicating about the body	Communicating with other palliative patients is normalising	4	
	Communicating with medics as a learned clinical style	5	7
	Communicating openly with family and friends	2	
	Protecting family	3	
	Friends and family ‘play it down’ or ‘over-react’	2	
The body under attack	Cancer as an intruder to the body	2	
		6	
	Treatment experienced as attack on the body	4	

Over-Arching Theme	Higher-Order Theme	N endorsing higher-order theme	N endorsing over-arching theme
Mind/Body relations	The body's betrayal	6	
	Losing synchronicity/ becoming divided	2	8
	Interaction between emotions (mind) and symptom experience (body)	3	
	Mind Over Matter (visualising the cancer)	2	

### Description of Themes

Refer to Appendix I for the full table detailing which transcript extracts contributed to each theme. The following sections present the eight over-arching themes and the related 26 higher-order themes.

*The Changed Body*

Reflecting on the experience of living with, and living in, a body that has undergone significant changes as a consequence of disease progression was a strong theme and perhaps the most predictable of the themes to emerge given the focus of the research. Eight of the eleven participants referred to at least one of the higher-order themes identified within the over-arching theme of the changed body.

*Frustration and distress at changes in the body's capacity to perform*

Four of the participants expressed strong feelings of distress and frustration that as a consequence of their changed body they now struggled to do simple every day tasks.

"I mean a lot of things become a challenge now that you wouldn't have believed, or I wouldn't have believed, 18 months ago. You know. But this is what it does for you I suppose... It is a frustration, yes. Especially things like putting your socks on, I mean it's a simple every day thing and it's something that you can't do." (Participant 2, page 7, line 13)

A number of participants had been exceptionally fit prior to their disease and there was a sense of loss for these participants who now felt unable to engage in exercise.

"One of the hardest things has been finding that your body just doesn't do what it used to do and having to manage your expectations, so you know, big things like

exercise are one thing, ... I've done some quite major health and fitnessy kind of things and then you go to the other extreme and suddenly you can't do that anymore, even bending down or getting upstairs, all those kind of things are taken away, and that's particularly, very frustrating" (Participant 11, page 7, line 36).

One participant commented on the speed of the changes that they had experienced in their body, noting how hard it was to adapt to these changes both mentally and emotionally at such a pace.

"One of the things you don't get with this is a lot of time to adjust, ... in a year I went from being fit, healthy, full time job, very on top of things, or so I thought, to suddenly having this body that doesn't do what I want it to do anymore and a year doesn't seem very long, whereas as you grow older, from 40 to 50 to 60, there's that natural adjustment and it's happened so quickly" (Participant 11, page 10, line 18).

*Relationship with the body becomes more explicit as a consequence of disease*

Six of the participants reported that prior to their disease they had not had much awareness of their body and would not have considered their relationship to it. The changes brought about by their disease had caused them to develop an awareness of the body that had previously just been experienced as dependable.

"I don't really think I gave it an awful lot of thought, all the time I was able to do things, go swimming, go on the bike, go walking, I think all the time you are alright you just get on with things really." (Participant 6, page 6, line 30).

"I was no great athlete or anything but it always carried me through a job or whatever it was I was doing, I had no reason to question it really until the cancer"  
(Participant 10, page 7, line 21).

*The lived-body is no longer experienced as predictable*

One of the reasons that the relationship with the body has to become explicit for the participants is that the body no longer functions in the same predictable ways that it did in health. Underlying this theme is a sense of losing control of the body. The participants no longer felt in charge of their bodies, they were now reacting to their bodies as best they could.

"I think that there's that thing that you've lost control, probably because I'm a bit of a control freak! But you can't necessarily make your body do the things that you want it to all the time." (Participant 11, page 2, line 25).

This loss of predictability was apparent to participants in a number of ways. For example, for some participants the body had previously represented a dependable entity that would heal when damaged and would respond to simple medications when they encountered discomfort

"If I had a headache and I took an aspirin then I knew that the aspirin would work and my headache would go, so I could control it... I sort of relied on my body to heal

itself and it usually did [laughs] this is why it's so bewildering when it doesn't now"  
(Participant 9, page 2, line 26).

Other forms of unpredictability centred on managing previously predictable body functions, such as eating and toileting, which had now become unpredictable (e.g. unanticipated diarrhoea or noises in the stomach).

"[I don't] want [rich foods] to upset my stomach... the consequences are wider, more obvious, need more management, so it's all those kind of things which, again, you wouldn't have thought about before, which you suddenly think 'if I put this into my body what's the impact? How will I manage it? When do I draw my line really?'"

(Participant 11, page 6, line 16).

This loss of predictability often caused participants some degree of social anxiety. One participant was struggling to manage experiences of profound fatigue and found himself falling asleep in public places. He experienced this as his body becoming unpredictable in a very frightening way.

"Well, this is it, who knows what's going to happen to you if you fall asleep on a bench in the middle of xxxxx. [Laughs] [Sighs] Yeah that is very, very... I find that very, very frightening. And it is getting worse. It is getting worse." (Participant 1, page 11, line 12).

*Changes in Self-Concept as a Consequence of the Changed Body*

Six of the participants reported that their changed body had a direct impact of their sense of self.

*The changed body as unrepresentative of the self*

In most cases participants who indicated changes in their sense of self were referring to their altered body image (n=5). There appeared to be a sense that the person in the mirror was no longer recognised as the self.

"I walk past the mirror or I look in the mirror in the morning when I get up, I mean it doesn't look like me, I mean I could show you some photos that were taken a couple of years before I was diagnosed and you wouldn't even recognise me, I mean I have actually spoken to people in the supermarket who have worked with me for years and they don't recognise me. So, it's altered my body image in that way" (Participant 10, page 7, line 4).

For four participants their body image had been altered by changes caused by medical treatments, including surgery (significant scarring, a stoma), medication (weight gain) and chemotherapy (hair loss).

"From the body point of view, everything that I thought I knew about myself I kind of lost and you know there is a grief that I'm not the person that I thought I was" (Participant 11, page 10, line 7).

*Changes in Social Role (due to diminished physical capacity)*

Two participants reflected that they had been people whose identities rested in part on their caring nature and caring behaviours.

"I've always been a carer person, like, my Mum's still alive and I've always looked after her and now she's having to help me, although we do pretty well together, that I get really fed up about, because I always rely so much on my Mum, and I worry about that a bit, that I will let her down. In some ways that keeps me going because I won't let her down." (Participant 3, page 7, line 4).

*Fear of the Body's Future State*

Most participant's seemed to feel that while they experienced periodic distress at the current state of their bodies, they could currently function adequately, cope emotionally with this current state, and in fact usually experience a positive quality of life. It appeared to the researcher that one of the factors that did impact most negatively on their current quality of life was the *fear* about disease progression.

*Fear of the physical experience of death (i.e. fear of suffering at the end)*

Three participants voiced a fear of the process of dying. All three of them indicated that they did not fear death existentially, but that they did fear the 'method of dying.'

“I am not scared to die.... [but]I do not wish to linger, I do not wish pain and to be, you know, sort of hanging around forever and figuring out if you’re going to die or not. That to me, a slow death, would be absolutely a nightmare” (Participant 4, page 3, line 1).

*“What next?” General fear of the body’s unknown future*

Three participants spoke about fears concerning ‘what might happen next.’ This appeared to refer to an anxiety about how the body would continue to change. This may have related to the anticipation of new symptoms, increased pain, further loss of bodily control and the degeneration of the body’s boundedness. Participant’s often indicated that they did not speak about these fears to many people.

“The thing that worries me more than anything else, which is a funny thing really when you sort of think about it, is ‘what happens next?’ You know, what am I going to experience next? How is it going to affect me? That is the thing that tends to worry me more than anything else. What is going to happen, say, in the future? How far in the future... well, no one knows, but obviously something is going to happen. I’m not going to be able to do this, I’m not going to be able to do that. Is it going to affect me? Which way is it going to affect me? That is the thing that tends to worry me more than anything else, you know, is what is the next step?” (Participant 2, page 7, line 28).

*Anxiety/rumination about the meanings of recent/current bodily-sensatory-experiences*

Nearly half of the participants (n=5) spoke about a heightened sensitivity to sensations in their body. Any novel sensation or bodily experience that seemed out of the ordinary had the potential to start a cycle of rumination around the possible meanings of the experience. Essentially at the heart of this rumination were the questions: Is this sensation/discomfort one that I would have had anyway (perhaps because I am getting older)? Is this sensation/discomfort indicative of disease progression?

"You know more is going to come, you know that your symptoms are going to get worse and you're going to get more unwell, so any little thing you're initial thought is 'what is this now?'" (Participant 5, page 6, line 26).

*Adaptation*

Five participants described positive ways in which they had begun to adapt their behaviours or thinking styles to helpfully accommodate the changed body.

*Learning to listen to the body*

This theme relates to an extent to two of the previously described themes. As noted above, in response to the changed, unpredictable body participants had developed a

more explicit relationship with their body. One aspect of this was a tendency to be increasingly sensitive to bodily sensations in a way that triggered negative rumination about disease advancement. However, participants' accounts of relating to their bodies also highlighted a more positive, adaptive 'tuning in' to their bodies. Here the individual became more attuned to their body's signals that they needed to pace themselves, this involved realising that resting now would lead to a greater capacity to remain active in the longer run of the day or the week ahead. This required over-ruling past tendencies to get everything done immediately.

"I'm a great one for working through, even flu and things like that, I would perhaps have a day in bed, but then that would be it, get on, take it sensibly, take it slowly, but just get on with life, and that is, well, I suppose, there [seems to realise something] *that* is the difference now, since I've been diagnosed I'm listening to my body.... Now, it's: listen to what my body is saying; do I want to lay down? Do I want to go out in the garden and do some gardening? And that, yes, *that* is a big change since my diagnosis" (Participant 5, page 1, line 24).

*Adapting plans and planning in advance: taking the changed body into account*

Two participants in particular contributed to the sense of the overall theme of adaptation by describing the careful and sophisticated changes they made in the planning stages before an event. Both women were younger than the rest of the sample and had always led active lives. Since diagnosis they had remained active but both had needed to make significant changes to the way they approached activities.

"I now have to think about just going for my groceries or the post office, whereas you wouldn't think about it before, I now have to plan every little journey. And also it tends to be a lot longer, I can't just nip down the shop, it has to be a big thing. So much more planning is needed." (Participant 3, page 6, line 27).

*Gaining satisfaction from adapted goals*

As well as listening to the body and altering plans and goals for achievement in any given day, it seemed that gaining a sense of satisfaction from these goals, even if they were modest by the standards the participant may have had prior to disease, was an important part of adapting to the changed body. Two participants discussed this explicitly.

"You have to have little goals, you know, nothing to spectacular that you know is asking more of nature than is likely to happen. But you have to have goals that's an aim I can have" (Participant 8, page 3, line 35).

*A Tug of War: Ownership of the Body*

This constitutes the strongest over-arching theme, with nine of the participants contributing to the construct. This theme describes the way in which the social, cultural and interpersonal actions of the external world impacted upon the individual's body-with-disease, compromising the privacy, control, knowledge and autonomy with which that individual had previously owned and possessed their body.

In large part this construct, in describing the external world acting upon the body-with-disease, relates to the medical interventions carried out by medics. It is important to identify the medics here, alongside the interventions they conduct, as they are key social actors who directly impact upon the individual's relationship with the body. These professionals occupy a position of expertise and skill that culturally entitles them to touch and treat the body, to hold knowledge about the body that the individual may not, and to ask deeply personal questions of the individual's body-state and functions, all from a position of power. This power arises from the cultural standing of medics and from the fact that they have the power to alleviate symptoms and distress and to potentially extend life.

*Losing private ownership of the body:**Threats to the privacy and boundaries of the body*

This theme relates to the loss of privacy that participants often experienced, due to having to share the details of their body's private functions (e.g. their bowel movements) and due to the fact that their bodies were often examined. Further, this theme relates to the fact that the body is often being breached in some way, by needles, powerful chemical treatments, or endoscopy or gastroscopy examinations.

"There's so much that gets done to your body once you're diagnosed, you know, I have, well, a phobia is the wrong word, but I'm a little bit nervous of needles now, I've had so many things stuck in me, prodded in me, that you almost want to try and reclaim it a little bit, it's like when I go to the hospital for my chemo, it's like pick line in, flush, the old routine and that's absolutely fine, but it's like you want to try and get something back almost because so many things get done to your body it's just sometimes nice to just be you and your body again without everything else that goes on around it" (Participant 11, page 7, line 10).

*Who knows best? Compromising informed choice and ownership of the body*

Five participants talked about feeling uncomfortable about the way that decisions about their treatment were made and knowledge was held back. One participant was given chemotherapy without his awareness. Another described being told she needed to have a pick line put in, having it put in, and then being told on the same day by another doctor that she didn't need it and having it removed. A further participant

reported that she was not ever told she that had terminal cancer. She received significant surgery to 'debulk a mass' and then was left to work out that she was dying from a tumour that they couldn't entirely remove by reading the leaflets she was left with.

"The doctors are wonderful and I can't speak highly enough of them but they can tend to intimidate a bit and also I feel that if you don't speak your mind then you will end up being whipped along with something that you're not happy with" (Participant 3, page 9, line 8).

### *Retaining ownership of the body*

Despite the frequent encroachments upon the participants' sense of owning their own bodies, three participants described ways in which they had held firm against pressure and thereby retained a sense of ownership of their bodies.

"Participant: I saw a very nice respiratory doctor, and this was over two years ago, and he wanted to fit me with a feeding tube here and I was having no problems swallowing, eating, drinking, I had the record at xxxx in xxxx for lung capacity, so was feeling quite good and I said jokingly, I can't have that I'm still wearing a bikini and he was horrified! I have to be funny! That is my way around this. And I said, I don't need a feeding tube and he disagreed totally, but two years down the line I still don't need one, and that would have sat there for two years." (Participant 3, page 8, line 20).

*Sharing the body's space*

Two participants demonstrated this theme, which provides an example of how deliberately sharing the boundaries of the body can be highly adaptive

In the first example a participant described letting her Grandchildren witness the injections she was receiving and then describes her reasoning:

“I think that can be a bit frightening to a child, I don’t want to push them to do things that they don’t want to do but if they’re comfortable and they want to see something or do something then let’s go ahead with it, and it was the look on their faces, because they watched granddad stick the needle in and they immediately looked to my face ‘is it hurting’, you know, and I was sitting there like that [shows a calm face] and they went ‘oh,’ that reassures them.” (Participant 5, page 4, line 13).

In a further example of this, the same participant described wanting her daughters to recognise that even toward the end of her dying she wanted them to treat her body as if it were her:

"It's like, I said to my daughter the other day, I said 'when the worst comes', she said 'yes Mum,' I said 'if I'm lying in bed and there's a few hairs on my chin, you will pull them out won't you' and that's the whole attitude we're trying to keep about it. I want my dignity, I want to look good, I want to look presentable, so don't think you can't touch me ever, at the end, and do things." (Participant 5, page 4, line 14).

*Empowering self through self-education and research*

Four participants found that by engaging in research and teaching themselves more about their disease they were able to exert more power during interactions with medics, knowledge provided them with greater confidence to question and broadened their knowledge of choices available to them.

"When I got the primary I went on Cancer backup [an online cancer support site] and looked at it and saw what the alternatives were etc etc, and when the secondary came I went on cancer backup again and I found out various things that I felt I should have been told but I was never told." (Participant 4, page 6, line 36).

*Communicating about the Body*

An open-ended question enquiring about participants' experiences of communicating about their symptoms was the only other question to be asked systematically of every participant besides the primary relationship to the body question. As such, a construct around this topic was always likely. Four participants did not have anything they wished to say on this subject. Seven participants recounted experiences that fell into one of four categories.

*Communicating with other palliative patients is normalising*

All the participants were drawn from day centres operating at a hospice and as a result all participants had experience in communicating with other palliative patients. Four participants reported that communicating with other patients in the day centres helped them understand and cope with their own symptoms better.

"You see you can't talk to people that have no knowledge of what you're going through, they just don't want to know, but the people who have been through it they know what you're talking about, that helps enormously, you don't feel that you are imposing your illness on them because they're going through it themselves, they know" (Participant 9, page 4, line 33).

*Communicating with medics as a learned clinical style*

Five participants discussed the challenge of tailoring their communication to medics specifically. Three participants also indicated how challenging it can be to describe bodily experience effectively.

"... with the doctors I'm looking for what they're looking for, and I'm thinking 'what do they want from me?' and I try to, and I probably tend to tailor what my answer as to what I think they want to hear. How can I explain it? [It's] not so much what information [I give them] cos I'm quite open about it and I will tell them what I

am going through but I try to do it in a way that makes sense medically" (Participant 10, page 3, line 5).

*Communicating openly with family and friends versus protecting family*

Two participants described their feelings about the importance of being open with family and friends about their experiences, while a further three voiced their wish to carefully limit the details of their physical experiences so as to protect family and friends.

"I know what's happening to me, my children don't and they imagine. They could be imagining it's worse or they could be imagining it's better, you know, and that's a difficult bit to breach, to get them to know that it's unpleasant but it's not necessarily doom and gloom ... it's not easy but if everybody knows the same thing you are all playing from the same rule game aren't you, you know every body is playing to that." (Participant 8, page 3, line 23).

"... then there's [my husband], and there's protection there very much and we'll talk about the fact that I'm tired, so when it comes to symptoms or how I'm feeling I'll tell him when I'm tired or if I'm a bit tearful" (Participant 11, page 11, line 31).

*Friends and family 'play it down' or 'over-react'*

Two participants described the experience of this theme.

"I found talking to family, friends and neighbours sometimes very difficult, because they do not understand. I've said, and other people here have agreed with me, friends, family, and acquaintances seem to fall into two groups; those that think you got a head cold and those that think that you should really be in your box."

(Participant 10, page 5, line 17).

*The Body under Attack*

Six participants made reference to a sense that some of their experiences since diagnosis had felt like their body was under attack from external agents.

*Cancer as an intruder to the body*

Two participants described their cancers *as if* the cancer was an intruder (rather than made up of their own cells), indicating a perception that the cancer was akin to an external attacking agent.

"[The cancer is] an intrusion, yes, it's something nasty, I've got to get rid of this, that sort of thing, I'm fighting it" (Participant 9, page 7, line 15).

*Medical treatment experienced as an attack on the body*

Four participants spoke about the damage that attempted-curative treatment or palliative treatment had caused to their bodies. There was a sense of this 'treatment' being perceived as an attack and a further threat to the body's wellbeing.

"Your body's ill but it almost seems to take a battering from every side, everything that is done almost seems like an attack, you know it's needles or medication or chemo." (Participant 11, page 7, line 20).

*Mind/Body Relations*

There were four themes that related directly to the mind/body relationship, each of which invoked a dualism to the mind/body relationship.

*The Body's Betrayal*

Six participants endorsed this theme. The essence of this theme concerns the participant's feeling that they have treated their body well and yet it has still let them down. There is a sense of unfairness at the root of this theme. Participants may have invested faith in a belief that a healthy life style, which often included engaging in exercise and abstaining from unhealthy foods and from smoking, should not lead to cancer (or other disease) and an early death.

" If you've looked after something you kind of think it will service you better and then you get slammed with the most horrendous illness which really is awful and you can do nothing about" (Participant 3, page 8, line 1).

*Losing synchronicity/becoming divided*

The two youngest participants, both of whom could be considered the most active participants and the most resourceful at adaptively planning their lives in light of their disease (see 'adapting plans and planning in advance' theme, above), indicated a sense that their minds and their bodies were no longer synchronised. That is, there was a sense in which the mind was not being perceived as fully embodied. Instead the mind (and perhaps the sense of self) were beginning to be pitted against the body, which could not do what the mind wanted it to.

"You feel your head should be able to make your body do what it wants your body to do, you know you should be able to make that connection, but actually if you have a thought that you want to do something, ... but suddenly my body is saying 'no', so some big adjustments there" (Participant 11, page 8, line 4).

*Interaction between emotions (mind) and symptom experience (body)*

This theme seems to tie in with the literature on the psychology of managing pain (Hasenbring, 2000; Pincus & Morley, 2001) and with general cognitive behavioural theory (Morley, Shapiro, & Biggs, 2004). Three participants reported that when they were feeling lower in mood, they were less likely to engage in activities that

enhanced their moods and, significantly, they experienced their symptoms as more distressing.

"I might walk in here feeling a bit rough but I might walk home feeling a lot better... I think mental and physical both go together. I think if mentally you're lightened it does take pressures off your body I think. You know yourself, if you've got a sore back, if you go out and have a laugh with somebody suddenly you've forgotten your sore back because you're enjoying yourself and that's what coming here does, gives you a sense of enjoyment." (Participant 5, page 7, line 30).

### *Mind over matter*

Two participants described a sense of attempting to use the power of their mind to influence their body.

"Well, I just visualise it as a mass and try to say to my mind 'shrink, dissolve, go away' sort of thing." (Participant 9, page 6, line 5).

## DISCUSSION

This study sought to describe the effect of a life-limiting diagnosis on an individual's relationship with their body. Analysis of 11 interview transcripts with individuals facing a life limiting diagnosis yielded eight over-arching themes and twenty-six higher-order themes that described the participants' relationship with the bodies.

*'The changed body'*, being a sense of the body as altered, was a major construct that was evident in the data. This construct was based upon: participant reports of feeling frustrated and distressed by the changed body, reports of a more developed awareness of the body (and particularly its limitations) compared to before the disease, and a sense that the changed body was no longer predictable, which led to anxiety and especially to social anxiety.

It is interesting that prior to disease the lived-body<sup>6</sup> does not appear to have been a construct around which participants organised their life narratives. However, following changes to the body and the loss of its predictability, it has become a construct around which the world *must* be ordered as evidenced by three of the other over-arching constructs that arose from the data; changes in self-concept as a consequence of the changed body, fear of the body's future state, and adaptation, which incorporates learning to listen to, and be aware of, the body in a more embodied, lived way.

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<sup>6</sup> The *lived body* is a concept of 'the body' as the point of experiential interface between sensation, cognition and the external world (Merleau-Ponty, 1962)

The fifth and, with nine participants endorsing it, most supported construct to emerge from the data concerned the individual's sense of '*ownership of their body*'. This construct included the experience of threat to their sense of ownership of the body as well as efforts to retain ownership.

In order to apprehend the importance of this construct, consider the following: For a healthy, able adult the body can be seen to belong unequivocally to them. They are likely to let only few intimate others compromise their private, boundaried space, they are likely to have times of the day when they complete routines of self care in complete privacy when they would not want even those most intimate others present, they can easily keep knowledge of their body's state of functioning private, and they are likely to know their own body better than anyone else. In the face of a degenerative disease all these assumed rights of privacy, boundaries, personal space and self-knowledge are likely to be forfeit at various times and with increasing frequency as the disease progresses. The participants in this study gave voice to the disempowering and distressing nature of this loss of power over their own bodies.

The sixth over-arching theme describes participants' experience of communicating about their symptoms. This was a construct that was broadly elicited by the researcher as each interview began with an open-ended question asking about the experience of communicating about symptoms. There were five categories of experience that were described by the participants as a result of this open-ended question. The strongest higher-order theme (or category of communication) described the manner in which participants carefully tailored their communication

during medical encounters to fit the 'business-like' nature of the situation.

Participants felt that they improved at such discourse with experience.

The seventh over-arching theme to emerge from the data detailed one way in which participants conceptualised their experiences. Here the body was seen as 'under attack' either from the cancer or from medical treatments.

The final over-arching theme described the participants' accounts of the relationship between their mind and their body. In the first higher-order theme of the over-arching construct of '*mind/body relations*', the body was seen as a betraying agent, (perhaps betraying the self or the mind).

This higher-order theme has a Cartesian dualism to it (Gold, 1985), depicting a mind and body in conflict, which is in opposition to the more adaptive, embodied theme of '*listening to the body*' that is located in the over-arching theme of '*adaptation*'.

Interestingly, a number of participants who had described themselves in the embodied sense of listening to their body were also amongst those that described their relationship to their body in the Cartesian terms of body as betrayer.

The next higher-order theme of the mind/body relations construct, '*losing synchronicity/becoming divided*', heightens this sense of dualism further. This theme refers to instances where the participant has described their mind willing their body to perform and the body being experienced as 'refusing to perform.'

This discussion of the mind/body relationship, and specifically the fragmentation of this relationship, echoes the work of Copp (1997), who found that participants close to dying, along with their nurses, began increasingly to characterise mind and body as separate and distinct. The self became a non-embodied entity in their characterisation of it.

This then raises a further question: what factors might influence experiences of embodiment in individuals with a life-limiting diagnosis?

The primary factor influencing this seems to be the changed and unpredictable nature of the body and the fact that, as Brodkey describes in his account of his cancer experience, the autobiographical memories of the self no longer relate to the body in which they now reside.

A further factor that may contribute to levels of embodiment, as indicated by the data of the present study, concerns the treatment of the body at the hands of others, particularly medics.

Gold (1985) states that a patient presenting with an illness loses certain specific freedoms over their body. This claim is in keeping with the experiences of the participants in this present study who felt that in turning their bodies over to the purview of medicine they were losing their sense of ownership. So, how might the clinical encounter, and specifically the treatment of the body within this encounter, be contributing to the experience of embodiment?

In the clinical encounter, the medical professional examines the Cartesian 'object-body' seeking the cause of pathology and attempting to apply an intervention to correct or compensate for this pathology (Illich, 2003). The patient, on the other hand, presents with a 'lived-body', situated within an experiential, phenomenological experience of disease.

Straus (1963) proposes that a result of the medical 'body as object' approach to this encounter is that the patient comes to regard the body in an objectified way. This possibility seems congruent with the manner in which some participants in the present study reported learning to communicate with medics about the body in a clinical way and noted that this was sometimes a difficult 'skill' to acquire. Perhaps something beyond just learning a new communication style is happening for these participants. Perhaps they are learning a new way of relating to their body.

Goncalves (1997), for example, highlights the power of language as the essential material from which narratives are built, emphasising that the nature and form of that language will impact upon the meaning that arises from the narratives it contributes to.

Perhaps to cooperate fully with the clinical examination of medics, the patient must purposefully take up this particular clinical, objectified manner of self-regard (MacLachlan, 2004). Contat, Sartre and Rybalka (1974) refers to this phenomenon when they discuss the gaze of the 'other' objectifying the body. This may create a conceptual conflict for the participants between their lived experience and what is being asked of them.

Gold (1985) argues for the application of the model of embodiment to medical practice. He stresses that the body should not be reduced to a Cartesian style mind operating above a mechanical body in the midst of the medical encounter, but instead should be approached as “multiphasic, experiential” entity (Gold, 1985, p. 664). Gold’s consideration of the impact of body objectification dates back nearly 25 years, yet the data of this present study suggests that it is still a topic that needs further discussion.

It is, of course, important not to overstate this argument. The current discussion only seeks to postulate connections between the constructs of ownership of the body, communication about the body, and mind/body relations. Further research would have to qualify this further.

### Clinical Implications

This study highlights the importance of managing the threats to an individual’s ownership of their body in a clinical setting. Given the necessarily invasive nature of most medical investigations and interventions it is unlikely that the experience of distress around this theme could be eliminated. However, altering aspects of the medical encounter on an interpersonal level by communicating with participants in an empowering way and approaching their bodies with deference and respect may alleviate some of the distress. This calls for an approach that responds to the needs of the whole person, attending to psychical, psychological, social, and spiritual aspects of the person’s experience in all medical encounters. Adopting such a multiphasic

approach to the body within the medical encounter, as Gold (1985) suggests, may permit the individual to retain greater ownership over their body and facilitate greater embodiment.

Further along these lines, some participants indicated a sense of being disempowered by the information that was held back from them. This reflects the findings and advice from a large body of literature about breaking bad news that already exists (for reviews on the established literature see Ambuel & Mazzone, 2001; Parker, et al., 2001; Ptacek & Eberhardt, 1996), however this study indicates that the best practice guidance on breaking bad news is often not being adhered to in many oncology settings.

It is not clear from the current research how adaptive or restrictive varying degrees of embodiment are upon an individual's quality of life. However, it is possible that applying acceptance and mindfulness approaches to the experience of the lived body may reduce distress (Hayes, Follette, & Linehan, 2004; Kabat-Zinn, 2003). Mindfulness may represent an approach that could facilitate mind-body connectivity, acceptance of the altered body, and could moderate rumination about the body. However, it is worth noting that in Copp's (1997) study, which explores the experiences of patients who were further along their disease trajectory than the participants of this study, the separation of the mind and body that was apparent could be interpreted as helpful in preserving the sense of the individual's self.

Chadwick, Newell and Skinner (2008) have conducted some early research into the effects of Mindfulness on participants in a hospice setting and found moderate benefits reported.

The research also highlights the importance of creating space for individuals to explore and make sense of the implications of their changed bodies and the related impact on their self-concept. This 'space' may be generated by professionals making time to such discussions and employing an open and curious, yet respectful, approach to the lived experiences of service users.

Finally, the research suggests meaning making narratives that may unfold in the clinical setting, particularly indicating the importance of constructs such as ownership of the body, the body under attack and the body's betrayal.

### Limitations of the Study

This research explored the lived experience of a small sample of individuals with a life limiting diagnosis. This represented an appropriate first step in an under researched area. This study does not seek to make generalisations about this population but instead hopes to lay a small part of the foundation for future research in the area.

It is important to note that the recruitment process for this research involved presenting to between 50 and 60 prospective participants and inviting them to volunteer. That only 15 of these individuals chose to participate means that at least 2

in 3 people did not wish to participate. It is possible that individuals who did not choose to participate in giving an account of their relationship with their bodies have different psychologies in some way. This may be that they are less confident at engaging in social interaction such as an interview or that they are more private about their experiences. It may be that they tend to reflect less upon their experiences, seek less meaning in them and do not use narrative processes to structure their experience. Alternatively it could be that they do reflect and narrate but have no sense of relating to their body even in disease.

So, while the analysis can potentially tell us about a subset of people, others (in fact the majority of those approached) may have a very different sense of their experiences. Further, individuals attending day centres at hospices may represent a group that is qualitatively different to those who do not attend. For example, clinical experience suggests to the author that some individuals are very frightened to even enter a hospice and these individuals may relate to their bodies in very different ways.

#### Future Research

There are two ways in which further research is suggested by this study. Firstly, there is scope to focus on a number of the constructs that were developed in the analysis and develop them further. For instance, does the degree of embodiment or the extent of the mind/body divide displayed by participants relate to measures of adaptiveness, coping or quality of life, either positively or negatively? It would also be valuable to know how an individual's relationship to their body developed further along the disease trajectory. Finally, no gender differences were apparent in the analysis.

Neither was there any clear sense that type of disease impacted upon experience.

Further studies may seek to look more closely at this.

The second avenue for further research is laid out by a number of further constructs that arose from the data but which did not relate to the participants' relationship with their bodies and, as a result, were not formally analysed. These include: variations in the presence and form of an existential acceptance of dying, benefit finding in the experience (especially in finding new perspectives on life and relationships), communicating with others in the face of disease, a recurrent theme about actively avoiding feelings of anger, the significant impact of prognosis predictions (both positive and negative) on quality of life, the increased saliency of emotional responses, and the impact of feelings of guilt, burden and concern for family on the individual.

### Conclusion

This study was able to generate a comprehensive set of rigorously defined and structured themes that described the lived experience of the 11 participant's relationships with their bodies in the face of a life limiting diagnosis. While generalisations to the wider population are not viable from this present study it was successful in generating possible avenues for further research.

### Final Comments

Following the interviews, a number of participants commented that the experience of engaging in these conversations with a professional (notably located outside of family and friendship groups) had felt interesting, satisfying and, at times, therapeutic. No therapeutic interventions were employed beyond the scope of giving the participants space to explore their stories.

This provides anecdotal support for the importance of facilitating meaning making processes for individuals with a life limiting diagnosis. It is fitting to end this discussion with an excerpt from an interview (see Figure 2 below) in which the participant spontaneously describes the active experience of relating to the world in a meaningful way in the face of disease.

Participant: I think in having cancer it does give you a totally different outlook on everything, not just on the cancer but on living and how you behave with one another, you know

Interviewer: Shakes everything up?

Participant: Oh, yes. You know a kaleidoscope, when you shake a kaleidoscope you get that picture don't you, and that picture stays with you and then you shake it again and you forget what the first picture was, because that's the one that's now in your mind.

Interviewer: And that's what it feels like, the kaleidoscope's been shaken and everything's rearranged and it's in different places

Participant: So, what happened then is not what's happening now and what's happening now, it won't be like this next

Interviewer: It kind of sounds like your experience has been that the kaleidoscope keeps getting shaken and you're saying 'what am I looking at now?'

Participant: Yes

Figure 2: Excerpt from Interview with Participant 8

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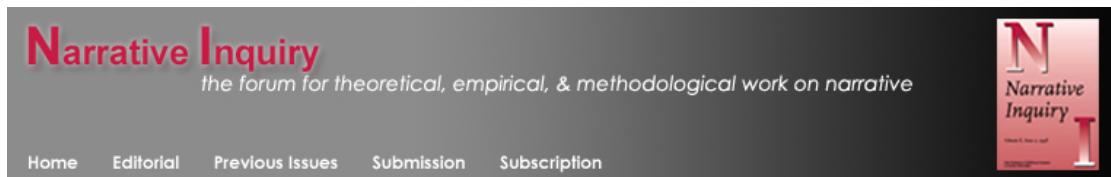
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## Appendix A: Guidelines for Authors (Literature Review)



Narrative Inquiry is devoted to providing a forum for theoretical, empirical, and methodological work on narrative. Articles appearing in Narrative Inquiry draw upon a variety of approaches and methodologies in the study of narrative as a way to give contour to experience and life, conceptualize and preserve memories, or hand down experience, tradition, and values to future generations. Particular emphasis is placed on theoretical approaches to narrative and the analysis of narratives in human interaction, including those practiced by researchers in psychology, linguistics, anthropology, sociology, and related disciplines.

Please send all submission inquiries to [narrinquiry@clarku.edu](mailto:narrinquiry@clarku.edu)

*Please send manuscripts to*

Michael Bamberg

Guidelines for Contributors:

1. Narrative Inquiry publishes exclusively in English.
2. Authors should submit four copies of their MANUSCRIPT, double-spaced (12 pt) and prepared according to the Publication Manual of the American Psychological Association (4th edition).

The manuscript should include an abstract and a covering letter stating the format of the contribution and the preference whether the author prefers the manuscript to be reviewed anonymously, or openly.

3. The journal publishes target articles along with invited commentaries, articles, research notes, unsolicited commentaries, review articles, book reviews and occasional announcements. Articles should preferably not exceed 8000 words (incl. endnotes and references). Notes and commentaries should not exceed 2500 words.
4. Upon acceptance the author will be requested to send the final version on disk (IBM compatible, preferably WP) accompanied by two hard copies of the text.
5. FIGURES and TABLES should be numbered, with appropriate captions, and be placed following the reference section. Reference to any Figures and Tables should be made in the text and their desired position should be indicated on the hard copy.
6. QUOTATIONS should be given in double quotation marks. Quotations longer than 4 lines should be indented with one line space above and below the indented

passage.

7. FOOTNOTES should be kept to a minimum; be numbered consecutively throughout the text.
8. To facilitate quick review of manuscripts, authors should submit a list of three possible reviewers. The addresses and telephone numbers of potential reviewers should be included. All submissions are screened first by the editors for an initial acceptance decision. Those papers considered to fit the scope of the journal are further reviewed by three independent reviewers. Submitted manuscripts will not be returned to the authors if rejected. If the manuscript is accepted, substantive commentaries upon the paper may be published simultaneously.
9. Manuscripts are received by the explicit understanding that they are original pieces of work and not under simultaneous consideration by any other publication. Submission of an article for publication implies the transfer of the copyright from the author to publisher upon acceptance.

Accepted papers may not be reproduced by any means, in whole or in part, without the written consent of the publisher. It is the author's responsibility to obtain permission to reproduce illustrations, tables, etc. from other publications.

10. Authors will receive a copy of page proofs for final corrections. These must be returned by the dates determined by the publication schedule. Authors receive one copy of the journal upon publication.

## Appendix B: Guidelines for Authors (Empirical Paper)

**Qualitative Research in Psychology**

<b>Editors:</b>	<u>David Giles</u>	Lancaster University, UK
	<u>Brendan Gough</u>	University of Leeds, UK
	<u>Martin Packer</u>	Duquesne University, USA

**Manuscript Submission Guidelines:****Notes for Authors**

Qualitative Research in Psychology aims to become the primary forum for qualitative researchers in all areas of psychology - cognitive, social, developmental, educational, clinical, health, forensic - as well as for those conducting psychologically relevant qualitative research in other disciplines.

Qualitative Research in Psychology is dedicated to exploring and expanding the territory of qualitative psychological research, strengthening its identity within the international research community and defining its place within the undergraduate and graduate curriculum. The journal will be broad in scope, presenting the full range of qualitative approaches to psychological research.

The journal aims:

- to firmly establish qualitative inquiry as an integral part of the discipline of psychology;
- to stimulate discussion of the relative merits of different qualitative methods in psychology;
- to provide a showcase for exemplary and innovative qualitative research projects in psychology;
- to establish appropriately high standards for the conduct and reporting of qualitative research;
- to establish a bridge between psychology and the other social and human sciences where qualitative inquiry has a proven track record;
- to place qualitative psychological inquiry appropriately within the scientific, paradigmatic and philosophical issues that it raises
- Qualitative Research in Psychology will publish the following types of paper:

1. Theoretical papers that address conceptual issues underlying qualitative research, that integrate findings from qualitative research on a substantive topic in psychology, that explore the novel contribution of qualitative research to a topic of psychological interest, or that contribute to debates concerning qualitative research across the disciplines but with special significance for psychology
2. Empirical papers that report psychological research using qualitative methods and techniques, those that illustrate qualitative methodology in an exemplary manner, or that use a qualitative approach in unusual or innovative ways

### 3. Debate section

### 4. Book reviews

Submissions for special issues will normally be announced via an advertisement in the journal, although suggestions for topics are always welcome. Book reviews will normally be suggested by the Book Review Editor, although unsolicited reviews will be considered and the journal will also review other relevant media as well as qualitative research software.

All papers are refereed by, and must be to the satisfaction of, at least two authorities in the topic. All material submitted for publication is assumed to be exclusively for Qualitative Research in Psychology, and not to have been submitted for publication elsewhere. All authors must assign copyright to Arnold (by completing the copyright assignment form). Priority and time of publication are decided by the editors, who maintain the customary right to edit material accepted for publication if necessary.

## **Submission**

Submit your paper by email to the following address:  
Email:[d.c.giles@lancaster.ac.uk](mailto:d.c.giles@lancaster.ac.uk)

All components of your paper (including tables and figures) should be contained within a single document (preferably in Word but files can be accepted from any of the common Macintosh, Windows or MS-DOS word processing programs). Please send two versions of your paper - blinding one version for peer review purposes (i.e., author names and affiliations removed). The editorial office accepts papers in either UK or US page size formats

## **Article presentation**

Manuscripts should be double-spaced throughout, especially the references. Pages should be numbered in order.

The following items must be provided in the order given:

### 1) Title Page

### Authors and affiliations

Authors should include their full name and the establishment where the work was carried out (if the author has left this establishment his/her present address should be given as a footnote).

For papers with several contributors, the order of authorship should be made clear and the corresponding author (to whom proofs and offprints will be sent) named with their telephone/fax/email contact information listed.

## Abstract

Please provide an abstract of approximately 150 words. This should be readable without reference to the article and should indicate the scope of the contribution, including the main conclusions and essential original content. This is not needed for observations or commentaries.

## Keywords

Please provide at least 5-10 key words.

## 2) Text

APA guidelines apply

## 3) References

APA guidelines apply

## 4) Acknowledgements

Authors should acknowledge any financial or practical assistance.

## 5) Tables

These should be provided on a separate page at the end of the paper and be numbered in sequence. Each table should have a title stating concisely the nature of information given. Units should be in brackets at the head of columns. The same information should not be included in both tables and figures.

## 6) Figure captions

These should be provided together on a page following the tables.

## 7) Figures

Figures should ideally be sized to reproduce at the same size. However, the typesetter can manipulate sizing where necessary.

All figures should be numbered consecutively in the order in which they are referred to in the text. Qualifications (A), (B) etc can only be used when the separate illustrations can be grouped together with one caption.

Please provide figures at the end of your paper on a separate page for each figure. Once accepted you will be required to provide a best quality electronic file for each figure, preferably in either TIFF, or EPS format.

For an information sheet about creating electronic versions of your figures please click [here](#).

## Style

### General:

Abbreviations should be spelled out when first used in the text. Full stops should be used in lower case abbreviations (e.g., i.e.,) but not for capitals (SAS, ANOVA).

Spelling can be either UK or US English but must be consistent throughout the paper.

### Mathematical:

Numbers below 10 should be written out in the text unless used in conjunction with units (e.g., three apples, 4 kg).

Use spaces (not commas) within numbers (e.g., 10 000, 0.125 275).

Full points (not commas) should be used for decimals. For numbers less than one, a nought should be inserted before the decimal point . (e.g., 0.125 275).

SI units must be used. English units may appear in parenthesis following the SI units.

## Permissions

It is the responsibility of the author(s) to obtain written consent from the original publisher and author(s) to use the following material published previously elsewhere.

1) All maps, diagrams, figures and photographs (forms are available from the publishers); 2) Single passages of prose exceeding 250 words, or scattered passages totalling more than 400 words from any one work. Please supply the publisher with full information for all work cited, including author, date published, publisher and page references. EU copyright extends to 70 years after the death of the author or 70 years after publication of a scholarly edition. Please forward all correspondence to the Journals Production Department, SAGE Publications Ltd, with your accepted manuscript.

Appendix C: NHS Local Research Committee Approval Letter



**National Research Ethics Service**

DC/MFK

**ISLE OF WIGHT, PORTSMOUTH & SOUTH EAST HAMPSHIRE  
RESEARCH ETHICS COMMITTEE**

29 September 2008

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Dear Mr Beadon

**Full title of study:** *An exploration of the effect of a life-limiting diagnosis on an individual's relationship with their body*

**REC reference number:** *08/H0501/75*

The Research Ethics Committee reviewed the above application at the meeting held on 19 September 2008. Thank you for attending to discuss the study.

**Ethical opinion**

The researcher is reminded that all documentation given to participants should be on headed paper.

Members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

**Ethical review of research sites**

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rforum.nhs.uk>.

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

*The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England*

Appendix D: Hospice Ethics Committee Approval Letter



Our Ref RW/8.82/JP

11 June 2008

To Whom It May Concern:

Re: An exploration of the effect of a life-limiting diagnosis on an individual's relationship with their body

Mr Paul Beadon attended The Rowans Hospice Ethics Committee Meeting on Tuesday 15 January 2008 to present the above research proposal. The Committee enjoyed meeting with Mr Beadon and discussing this proposal.

After lengthy discussion and due consideration by The Rowans Hospice Ethics Committee Members it was unanimously agreed to fully support Mr Beadon's proposal to undertake this research project, subject to LREC approval.

Yours faithfully

Ruth White

Ruth White

Chief Executive

## Appendix E: Participant Information Sheet

**An exploration of the effect of a life-limiting diagnosis on an individual's relationship with their body****Information Sheet for Research Participants**

You are asked to read this form carefully. If you consent to take part, as a participant, in the studies described here, then you should sign the consent form, a copy of which will be given to you. If you have any query, or are uncertain about anything, then you should not sign until your problem has been resolved and you are completely happy to volunteer.

**Details of this study**

I am Paul Beadon, a Trainee Clinical Psychologist, and I am requesting your participation in a study that seeks to describe how people with a life-limiting diagnosis relate to their bodies. So far there has only been a relatively small amount of research done on the ways that people with life-limiting diagnoses feel about their experiences. This present research seeks to look specifically at how people with a life-limiting diagnosis relate to their bodies and hopes to contribute towards increasing what Psychologists know about these experiences.

The research that you are being invited to participate in would require you to be interviewed, by me, for between an hour to an hour and a half. During the interview you would be asked to share any feelings, thoughts, ideas and experiences you have had, or are having, with regard to your relationship with your body since learning of your life-limiting diagnosis.

This interview can take place either at The Rowans Hospice or in your own home, dependant on where you would feel most comfortable. These interviews will be tape-recorded. Should you wish to take a break during the interview or complete the interview over two or more meetings this can easily be arranged. Your participation is entirely voluntary and you may withdraw your participation or choose to end the interview at any time. You do not have to give any reason and no-one can attempt to dissuade you. If you ever require any further explanation, please do not hesitate to ask.

Personal information will not be released to, or viewed by, anyone other than to the researchers involved in this project. The researchers involved in this project are myself, Paul Beadon, and my supervisors; Christine Kalus, Consultant Clinical Psychologist, and Professor Peter Coleman, Professor of Psychogerontology at the University of Southampton.

Any information obtained during this project will remain confidential as to your identity: if it can be specifically identified with you, your permission will be sought in writing before it will be published. Other material, which cannot be identified with you, will be published or presented at meetings with the aim of benefiting others. All information will be subject to the conditions of the Data Protection Act 1998 and subsequent statutory instruments.

If you have any questions please feel free to ask them now or on the day of the interview. Alternatively you can contact me, Paul Beadon, by leaving a message for me with Shelagh Jenkins at The Rowans Hospice (telephone: 02392 250 001) and I will get back to you.

Sincerely,

Paul Beadon

Trainee Clinical Psychologist

## Appendix F: Participant Consent Form

## Consent Form for Research Participants

**Statement of Consent**

1. I have read the information sheet, which provides full details of this study, and have had the opportunity to raise and discuss my questions with the researcher with regard to the general nature, object, potential risks and duration of the study, and understand what is expected of me.
2. In signing this consent letter, I am not waiving my legal claims, rights, or remedies.
3. I understand that the aim of the study is to seek to describe how people with a life-limiting diagnosis relate to their bodies.
4. I agree to volunteer as a subject for the study described in the information sheet, and I give my full consent to my participation in this study.
5. This consent is specific to the particular study described in the information sheet attached, and shall not be taken to imply my consent to participate in any subsequent study or deviation from that detailed there.
5. I reserve the right to withdraw from this study at any time without penalty; I also understand that I may be withdrawn at any time, and will suffer no penalty as a result. I do not have to give any reason and no-one can attempt to dissuade me from withdrawing.
6. I agree to my participation in this study to be audio -recorded.
7. I understand that these audiotapes will be destroyed after analysis.
8. I agree to the use of anonymous quotes in publications.

I understand that if I have questions about my rights as a participant in this research, or if I feel that I have been placed at risk, I can contact the Chair of the Ethics Committee, Professor Roger Ingham, Department of Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: (023) 8059 5578.

**Name of volunteer**

**Date**

**Signature**

**Name of Researcher**

**Date**

**Signature**

## Appendix G: Opening script

“Thank you for agreeing to meet with me for this interview today.”

“I’m going to get things started today by giving you information about the interview process and letting you know what to expect. Please feel free to stop me and ask questions as I go long.”

“As you know, this interview will contribute to my research. I will be recording our interview and after the interview I will turn the audio recording into a written transcript of the interview. When I write up the interview I will remove any information that identifies you, like peoples names and the names of places. The information you give me will then remain anonymous and the recording of our conversation will be deleted.”

“I think that the interview will take about an hour but this is only a rough guide, it can be longer or shorter. If you become uncomfortable or tired and wish to reschedule the interview or continue it on another day then this is absolutely fine. It is very important to me that if you feel that you no longer wish to take part in the research or would like to stop the interview that you feel able to tell me. I will not mind at all and will be happy to delete any recording of our interview while you watch.”

“During the interview I will be very interested to hear about your experiences and about your thoughts, feelings and ideas about those experiences. There are no right or wrong answers at all as this interview is about you and you are the expert on you.”

“I am aware that people may experience very difficult thoughts and feelings around the subject of their relationship to their body. You are free to share anything about this you would like without fear of judgement but also of course you can decide to keep anything private that you want to, I will respect and be sensitive to any wish you have to move on or away from any particular part of our discussion.”

“Do you have any questions so far?”

“This interview is about peoples relationship with their body when they have a life-limiting diagnosis. This is quite a general topic, it can mean different things to different people. I have several questions and prompts that I have prepared which may help us consider your experiences around this if we get stuck, but generally speaking this interview will be a conversation about your experiences.”

“To begin then: could you tell me about your relationship with your body?”

## Appendix H: Sample of an Interview Transcript

**Transcription of Interview with Participant: 11**

<b>Interview Date:</b>	<b>14/04/09</b>
<b>Interview duration:</b>	<b>1 Hour</b>
<b>Gender:</b>	<b>Female</b>
<b>Age:</b>	<b>42</b>
<b>Primary:</b>	<b>Bowel</b>

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I = Interviewer

P = Participant

[Interviewer reads pre-interview script]

I: To begin then: could you tell me about your relationship with your body?

P: I think probably before my illness I had quite a healthy relationship with my body and if anything I was probably a little bit complacent for want of a better word, I've always been reasonable healthy, I've always been reasonably happy with my body image, so probably it wasn't something I gave a lot of time to thinking about particularly. You know I think there's two aspects to how you look at your body actually, you know, the well being, so the fact that I was always very well, I was always very fit, very able and thought I'd live to a long healthy old age because other members of my family had, and then there's the other side of it, perhaps how you feel about yourself, probably on a day-to-day thing it's weight issues, it's how you look, what you look nice in, clothes, and I guess on that side of things, up until the illness, I was reasonable comfortable, I mean everyone has there fat days and everyone has moments of not being happy with how there body is working, but you know, generally I was coasting along without a care in the world I think it would be safe to say

I: It's very interesting, often during the course of the interview those two different aspects of the body get brought up, and today you've acknowledged them straight away; the body as something which is healthy and performs for us, but also the body as the image of us, who we are and our self esteem and it sounds like what you're saying is that prior to your diagnosis a sense of taking your body for granted, as dependable, as in health is the way 99% of the time. And with the body image thing it sounds as if it was fairly standard, you had your days when it was more difficult but generally speaking it was a comfortable relationship. How has the diagnosis changed that for you?

P: I think from the health point of view... 'let down' doesn't seem quite right... but yeah, I suppose I do feel a little let down by my body. It has been a bit of a shock that perhaps I'm not as healthy as I thought I was, I mean you do all the things they

say, I've never smoked, I've always kept fit and healthy, I haven't really had any physical illnesses particularly, other than a little bit as a kid, but generally ok, so it has been a little bit of a slap in the face that suddenly my body has decided to almost turn on me a little bit, and you know, it's something you can't control, so if you take a headache you take a tablet, you know, and with lots of ailments, there is something that fixes them. I think that with cancer you're very much aware that something can't be fixed. So there is a fact that your body has almost given up on you a little bit. And there is that element of you know, could I have done something different, if I'd have gone sooner, but that's something I don't go to close to because it doesn't change anything, but you know you think 'did I miss some signs if I hadn't been so wrapped up in life and, you know, listened to my body a bit more', would I be in a different position than I am now because if they catch it a bit earlier they can do different things, so there is that bit like your body has turned on you a little bit. Because most of the time you're not aware of your body, you know, when something hurts you feel it, but most of the time you don't feel your body particularly, you're too busy with life to even think about it. But unless something is actually hurting we really don't pay that much attention, well, I certainly didn't. You're just getting on doing what you should be doing, so I think I'm very much aware of how things feel now. And it's weighing up the balance now as to 'is this normal', because I would have got aches and pains at my age or is this because now my body's not as well as it was, and so you have to listen and probably look much more closely now as to what is going on as to how you would have done before I think

I: So, in that sense, in health the body wasn't something you needed to listen to, it was just there, and since you diagnosis it's become something you're more in tune with, and that sounds like in part it's sort of a careful listening for things you might need to listen to but also a sense that sometimes you almost over listen, you notice something about your body and then the question is 'is that ok, is that just because I'm tired and it's part of where I am in life anyway'

P: Very much so, you do kinda question your judgements more, you're a little less confident in what you might be thinking or recognising I would say.

I: Something else that you said which echoed at least one other person I have interviewed was the idea of that in health if you have a headache you take a tablet the headache goes away, I guess that they were, and you may be talking about something slightly different, but talking about being able to rely on their body, I do this and that happens, a certain predictability, but since diagnosis that had changed.

P: I think that there's that thing that you've lost control, probably because I'm a bit of a control freak! But you can't necessarily make your body do the things that you want it to all the time. So very much, if you've got a headache you can keep functioning, you take something for it and you kind of know what the results going to be, especially because I think I generally was quite respectful of my body, you think, 'well, come on, I looked after you and this is what you give me in return', yeah, there is that little bit of loss of control, you can't quite make it do what you want it to do, when you want it to do it. It's not as simple as taking a tablet, it's kinda got away from you a little bit, you can't manage the circumstances around your body quite so much perhaps. Does that make sense?

I: Absolutely, yes. I guess we live in a society where it's taken for granted that we will have a certain control over our body all the time and to lose some of the predictability of that must be quite, um, bewildering or...?

P: Yeah, and I guess one of the things I try not to do is to get too angry about it, you could get really angry, you know, and get caught up in the 'why me, I've never smoked, I've never done this, I've never done that' so, you know, 'why me' kinda thing but it really doesn't add any value, it did make me look back a little bit and I have to say there is a portion of it that I blame my mother for, because I lived in an environment which was always full of smoke, she was a chain smoker her whole life, until I left home, so I kinda make some links now about stuff maybe earlier in my life that I didn't have control over has had an impact on my body now and there's nothing I can do to fix it, I can't change it so I just kinda have to accept it. So there is that part of me that goes back and thinks 'well, I did my best to look after my body but there were circumstances beyond my control and I wonder how much of that now is an issue'

I: So parts of your environment, particularly as a child, when I guess other people should be looking after your environment that may have made you more at risk

P: Yes, I think so, I know I have very strong views on my friends smoking in front of their children and what they give them and things like that. Because you don't think about it, you can't control it as a child and you don't know what you're storing up for the future and I think if anything it highlights probably we do know about our bodies, we think we know a lot in this advanced society but if it still wants to come along and catch you out, it does

[pauses]

I: At the beginning of the interview you also mentioned body image as well, has that had an impact?

P: In someways that's probably the tougher part I would say [pauses for a while to think] it would have been wrong of me to say it's because of the type of cancer I've got because I think that everyone is different you know, a woman with breast cancer losing a breast must be as devastating as for me having to deal with some of the body issues I have that are probably slightly different, so I mean for me from a body image point of view, yeah it did, it hit me hard, mainly because I've got to have a [colostomy]bag for life, so I think if I had to pin it down that's what it is, that with cancer being on the inside you can kind of hide it a little bit and I think what it is, is that outwardly **I** can't disguise it, it's there. The bags there, it isn't going anywhere, that's it, and I think part of the issue is that I was given some false hope that it might go and so that kind of chucked up a lot of stuff, but the fact that the bag is there and it is very visible for me, don't want anyone seeing it, don't want anyone really being aware of it, and I did spend sometime thinking, you know, what is the issue with it, and I think it is an impact on my femininity, I think the fact that it is a waste product as well so you know, something that would normally be very private and very personal, your having to discuss it with the world almost and doctors and getting used to managing it and changing it and obviously its not as simple as just getting a bit of an upset stomach, and all those kind of things that would normally be really, really private, you're suddenly having to have all those conversations with people, so that's one side of it, but there is also my relationship with [my husband], where you

know, I still want him to see me as his wife, his attractive partner, and the bag really is a barrier to that, very much so, so I think from a body image point of view that was really, really, difficult. And to start with as well the scars were an issue, because I've got a massive scar from my operation, when I first went in they said 'oh, we might be able to do keyhole' and because of how much it had spread around I was literally opened from the chest bone down to the naval, the scar is huge, and I got past that a little bit and my friend showed me her scars from having a caesarean, so I could kind of manage that, you can kind of cover it, it's more manageable, but certainly the bag was a problem for me very, very much so, and is probably even one of the toughest things

I: So, a number of different important parts of your experience there; the privacy aspect which I guess I can really imagine, that sense of it is a very private thing, for something that is very private to suddenly be open to discussion must feel very alien

P: Very much so

I: Maybe very vulnerable, which I guess links in with the impact on your sense of femininity as well, and I guess I get the sense of it creating a barrier between you and [your husband] sometimes as well.

P: The thing is, as well, for him it isn't a problem, it really isn't, and although I've never shown him, because the nurse wanted me to actually show him the stoma, so the opening into my actual intestine but I thought: 'oh! You're havin' a laugh! It's never gonna happen' I don't want him to see the bag, so he's certainly not seeing that, she was very much to the point of 'it'll help, if at some point you can't manage it he needs to manage it' well, we'll cross that bridge when we come to it, I'm not planning on being that feeble just yet but I think he would, he wouldn't be repulsed, I'm sure, but this is very much about me, about me putting the boundary up, the barrier, yes, that's very much brought on by me, and I think, you know, it got such a problem when they said the bag wasn't going anywhere that I had to do something about it, I did have a few conversations and spoke with a nurse at the hospital and kind of brought that barrier back a little bit, that I will discuss it [with my husband], but I would still say that very much he respects my privacy, that when I get ready for bed he wouldn't just walk into the bedroom without knocking, without being sure that I'm ready for him to come in, without a nightie on or whatever, so he's very much aware that I don't want him or anyone else to see/be aware of I think and I wouldn't really move very far from that if I'm very honest about it, I might have moved on a little bit, not massive strides in that direction

I: So, it has become something you can talk about more but visually, as part of you, it's something that at the moment you wish to keep to yourself

P: Yes, and it has meant as well that I've had to review absolutely everything I wear. So, again, I was one of these people that would pretty much go out there and buy anything she wanted as long as I liked it I would feel comfortable in it but now I have think about lengths and things, no more bikini's and such, so I thought 'what about a tankini' but no, you still get that gap, so it had to be a one piece, so alright, that doesn't sound like the end of the world, but it's all these things that you're having to make adjustments, it's about the fact I don't have a choice about going to a one piece or buying longer tops or thinking about the thickness of the material, I have to now, so just thinking 'oh, that's pretty', I have to think 'no, I can't wear that

anymore' and one of the things that I did during the winter was I packed up a lot of my little summer tops and got rid of them because I knew that come the summer it would be like even more of a slap in the face because I couldn't wear them anymore. So, get rid of them when I'm not going to be wearing them, but again, they're the kinda things that you used to take for granted a little bit. Then you have to look at it with a different pair of eyes almost.

I: That sounds like there's a real sophistication with which you approach what to wear, there's a lot of variables in there, and also a sophistication in being aware of some of your feelings, i.e. 'if I have to do this in the summer that's going to be really awful so I will do it now' and preparation, both emotionally, and thinking about how you chose to present yourself.

P: It's little things that you wouldn't think about that I probably very rarely now try anything on in the shop, so I'll buy it and then take it back or I'll order online, so again, things that would have been a nice experience, I mean I still enjoy shopping, of course I do, but I don't want that let down of putting something on and it's not right and I'm in a public place, so before going into a woman's changing rooms wouldn't have been a particularly big deal but now it's like I don't necessarily feel comfortable or secure or confident enough, so again you just have to change the way you approach things a little bit, so that it doesn't knock your confidence too much. I went shopping one day and I bought everything, knowing that I could take it back because I didn't want the disappointment and wanting to still have a nice day shopping, so I thought 'right, but it all, I'll worry about it later' but you did have to really adjust how you approach what you wear, how you wear it, how you feel about it

I: How do those sort of adaptive plans occur to you? Are they things you learn as you go along, when something upsets you or is difficult or do they tend to be things that you predict ahead in you mind?

P: I think it's a bit of both. I think I was very aware that I wasn't going to be able to dress the same so I probably did plan and predict that a little more and I tried to make more of a plus on it, I thought 'oh, new clothes then, I'll buy something new' so I think there's that but then there's times when it will just catch you unawares and things that perhaps you haven't thought about, and that can be something like planning being away for a weekend, so thinking 'have I got enough things that I can cover myself up and if the weather changes' and things perhaps that you would not give a lot of thought to in the past, you perhaps have to think a little bit more. Again, going back to the bag you have to think 'have I got supplies, have I got everything I need in different sizes and where are we going', that's another things that it has an impact on, you almost have to think 'where am I going? Will there be somewhere that if I need to change I can change that I feel secure'. It's not just a loss of control, it's that you can't just go with the flow, you know, there has to be a little bit more planning there, but you do just get into a routine and I'm not as anxious now as I used to be. So we're going to stay with my in-laws, I was really anxious the first couple of times, it's having to get rid of the embarrassment factor, it's like having to get rid of the bag, something like that, [my husband] was great with that, but again, they know, they never mind, they'd never do anything to embarrass me, but for me that isn't something I want to be having a public discussion about or having people be aware of, I'm already thinking, we're going away for a week in September to a cottage, and

again I'm already thinking 'how will I manage this and what do I need to think about and how will I deal with getting rid of things.' It can be a pressure, it certainly can take the fun out of things a little bit, and again, thinking about what have you got to wear, making sure you're covered and things like that. So I think there are some things you do respond to because it catches you out and you're not prepared for it but you do get used to it, you have to adapt. If you don't adapt you die don't you, for goodness sake, so you have to make the adaptations it's just not always a particularly pleasant experience I think it would be safe to say. So, it can be very tiring, it can be very, very tiring.

I: I hear that, the resources that you have to use to adapt to things. I am also really struck by how much you do adapt to things, you've talked about it making you anxious sometimes, but that being something that by continuing to do you've streamlined your approach and you feel less anxious

P: I don't like to be beaten down, it's almost like, well, obviously I don't know how long I've got and I try and look on the positive, but I think we are where we are, and I've got two choices, and sometimes it does, of course it does, sometimes I'm on the floor, but I think you know, 'this is how it is', so I can almost choose to live the best I can with it and make some nice memories and have some good times... and I think that is the one thing that has moved on slightly, I probably am learning to have a bit more fun, so when I do go out with my friends, probably because I had that little preparation, I'm thinking before 'have I got everything I need', then I probably will relax a bit more. Certainly one of the things you have to think about, which I didn't think about before, is what you eat, it sounds so small and I don't know if it's the same with all types of cancer but certainly with the bowel cancer and the bag what you do to your diet can have a real impact on how busy your stomach is, so again, how relaxed you are when you are out and are enjoying yourself, I will think very carefully about what I order, how much I eat, because I don't want to deprive myself, for goodness sake I've got cancer I might as well eat what I want

I: So, really looking to find that balance between enjoying...

P: Exactly, the richness of something, I mean my father-in-law is a fabulous cook so he'll always try, especially because my taste buds have been affected, and the steroids sometimes make you want to eat like crazy, but it all tastes horrible, so he'll try and put a lot of flavours in things, so again, it's balance, so he's perhaps made something quite rich, don't want it to upset my stomach, not so bad again if I'm at home by myself, I'll deal with it, if you're out with people, again, it's this little thing in the back of your mind that ticks away, that you wouldn't have to give a thought to before, you'd go out and think 'I'm going to have a night on the drink and the food and if I feel a bit rough tomorrow it doesn't matter', now the consequences are wider, more obvious, need more management, so it's all those kind of things which, again, you wouldn't have thought about before, which you suddenly think 'if I put this into my body what's the impact? How will I manage it? When do I draw my line really?'

I: Right, sounds like you've developed kind of an ever-present part of you that's evaluating the cost/benefits... 'if I eat that it might be delicious but what will it do to my tummy, how will I manage it'

P: Yes, right, and it's also doing it without drawing attention because I know if I said to my in-laws 'I won't have another piece of that today' or 'I'll have a smaller bit because actually...' that would be fine, but I'm not comfortable doing that so again I find my little ways around it, I might just eat it and think 'we're going to go home tomorrow, it'll be alright' or I'll say 'I'll have a tiny bit now and a bit more later', so I'll find ways of management because I don't want to draw attention to the fact that this is about the cancer and I've got the bag and how it might effect my body and I'll be embarrassed if I get an upset stomach, so it's finding ways of not hurting peoples feelings and feeling that you're joining in and that people aren't thinking 'what's up with xxxx, she's not eating like she normally would', so it's finding little trick or techniques, and I might say to xxx sometime, 'back me up with this, don't order too much' or something, just so I can manage it, so it is just finding tricks and techniques just so that it feels normal and I'm not drawing attention to the fact that actually there is an element of anxiety there, I'm having to think about what I'm doing, eating, drinking

I: And it sounds like there's an awareness that most people would probably react very acceptingly if you voiced your anxieties but there's a sense that, nonetheless, it is important for you to make it seem regular

P: I feel very much that this is mine. I own it. So, again, a lot of it is the privacy, and maybe if it was something different I wouldn't feel it quite the same way, very much everything is around people looking at me and almost not seeing the fact that I've been ill or that I've got cancer, but certainly with the bag just not being aware that I'm wearing one, I think that's mine, I own it, I'm not quite prepared to share it almost, it's mine to deal with, maybe it would be easier if I did share a bit more but that's just something that I'm not comfortable doing

I: When you talk I can imagine that on one hand it would be easier for you if you were able to talk about it and on the other hand this sense of your body belonging to you and you wanting it to stay that way

P: There's so much that gets done to your body once you're diagnosed, you know, I have, well, a phobia is the wrong word, but I'm a little bit nervous of needles now, I've had so many things stuck in me, prodded in me, that you almost want to try and reclaim it a little bit, it's like when I go to the hospital for my chemo, it's like pick line in, flush, the old routine and that's absolutely fine, but it's like you want to try and get something back almost because so many things get done to your body it's just sometimes nice to just be you and your body again without everything else that goes on around it, does that make sense?

I: Yes, it does

P: Yeah, so much seems to happen to you, and so it's almost like I want to have a little control over that and almost pull away a little bit, I'll obviously never refuse anything that's offered but it does, your body's ill but it almost seems to take a battering from every side, everything that is done almost seems like an attack, you know it's needles or medication or chemo, so my friend summed it up, I was very upset when I started the chemo and I was so, so poorly, and she said you've almost got to see your body as a bit of a battlefield and the good guys are punching the bad guys out and it just means you don't feel very well, and in some ways that helped because I was seeing the chemo, not quite in a negative sense but I was still feeling

ill, I'd had the tumour out, I'd had all this recovery, I wanted my body almost to start getting back to normal, and then they hit you with all this stuff which makes you feel ill, and then she said about seeing your body as a battlefield and I thought 'yeah, that's not a bad way of looking at it', you know, if I'm feeling ill maybe the cancer is feeling quite ill as well, and that kind of got me through the early days of feeling unwell and feeling like I wasn't moving forward, because you know, you have this surgery, you have the recovery, then it's like 'I want to start getting better now, to start going out, to start doing things' and then they hit you with this next lot and everything starts to feel like it's not working again.

I: It sounds like that then, felt like you were being attacked, like your body was being attacked again, but the imagery your friend used helped you balance that a bit, thinking 'yeah, my body's having a rough time gain' but kind of reimagining what that means

P: Yeah, and the reasons behind it, yeah, very much so.

I: Sounds like it was really helpful

P: Yeah, it was. It was. But one of the hardest things has been finding that your body just doesn't do what it used to do and having to manage your expectations, so you know, big things like exercise are one thing, I stopped going to the gym because I had the dogs, but I used to be a real gym freak, I loved to exercise, I've done the London marathon, I've done some quite major health and fitnessy kind of things and then you go to the other extreme and suddenly you can't do that anymore, even bending down or getting upstairs, all those kind of things are taken away, and that's particularly, very frustrating, because you feel your head should be able to make your body do what it wants your body to do, you know you should be able to make that connection, but actually if you have a thought that you want to do something, and I'm sure that for anyone who has any kind of disability they would laugh at that, but if you've never had a restriction before, my head tells me to walk over there and pick something up and I should be able to do it, but suddenly my body is saying 'no', so some big adjustments there

I: So there's a break between the synchronicity of the mind and the body, the mind thinks it wants to do something but the body can't respond as it used to, the mind has to listen to what the body can do

P: Yeah, and it is finding the balance and it's recognising that yes, on some days you'll be able to achieve that and on other days you won't, and again that's quite difficult to accept, and I've got a bit better at it, I do rest now, because the way I look at it is that actually when my body is feeling stronger I will maximise that time when I can, but I have to accept on the days... and I think that sometimes it's thinking 'well, actually it's not necessarily my body's fault, they've chucked loads of chemotherapy in me, what do I expect,' so I think it's recognising that it's not actually me and my body, it's this stuff they've pumped in me, how do I expect to feel?

I: It's sounds like a recognition of the importance of giving the body a break and giving yourself a break, 'it's ok that my body can't do this, it's ok that I can't do this, it's actually alright to recoup from this over time'

P: Exactly, and I think that it is cause and effect, and I think that you have to focus on that a bit more and say 'well ok, I can't do a few things, but the reason I can't do it is that I'm having chemotherapy' and if that means that my body is better on some days then that's fine, and I think that it is actually not just thinking 'I can't do something' but actually thinking about why, analysing that, understanding the reasons behind it rather than it leaving you feeling defeated does that make sense?

I: That sounds like a different type of adjustment for you, instead of thinking about how you do things it sounds like you are thinking about changing your expectations of yourself, sort of bring a more kindly, gentle approach to yourself

P: The only down side of that and something that has perhaps caught me out once or twice when I've felt particularly unwell is, there is very much a fear of the future, if you look at it, so what about if I can't do that in the future, if your body does start to fail, so your pain gets worse, your condition gets worse, your less able, less able to manage things, less mobile, so I think that a lot of this, and again this is one of those things which is 'over there a little bit' – I don't go too close to it, but there is that almost fear that at some time my body may break down even more on me, and I really don't know how I'll manage that, I kind of manage it now because I see it very much as a step forward and I hope to maintain my current condition, stay as well as I can, but there is that concern, and you see it obviously with other patients, it's very difficult to ignore, at some point peoples bodies break down on them and normally you would hope that would be something connected with old age and for me it's very much not connected with old age, so you know, I'm very aware that at some point my body might just sort of age on me, I'll be old before my time, I'll be less able, there'll be pain management that I'm not having to deal with at the moment. I think a lot of this you manage because you have to, to live your life, but there is that danger, it does give you some food for thought, how will you deal with that, that's why I kind of park it, but if I'm honest there's that little bit that sort of ticks away back here and if I'm particularly unwell and particularly unable to do things then that's when the fear can really kind of start and the thought that at some point I really won't have control over my body and I won't be able to do what I want to do and with that comes lots of other issues and that's when I keep it at a distance because it is very frightening

[pauses]

I: Ok, well, that brings me to a question about emotions, because I guess emotions are experienced in the body, they're a bodily response, and I'm curious about how/if your experience of emotions have changed since your diagnosis?

P: Yes, very much so. I've definitely flipped the other way from how I was. I was a crier, I was a better out then in, I always believed that it was better for the body if you felt emotion to let it out so I was never one of these stiff-upper lips, I always felt if I needed a cry then I would have it and if that meant I would sob for two hours until I was exhausted then I would, and I always considered it a good release, I was always much of a mind that it was bad for your body to actually store up negative emotion, to suppress things, never been one for suppressing things particularly, it could be the simplest thing, 'little house on the prairie' I'd sob! And I always considered it a real plus for me, for my well being, and I would think definitely now I've gone the other way and I would think that for me now tears are a complete

negative, and I'm very aware that a lot of conversations I have, I can almost see it, I put down a steel wall so I can talk about things and I can feel the emotion ticking away, I can feel it in this interview, but because I've brought the barrier down the tears won't come. For me I'm very visual, so if I picture an image that's when the emotions will over run me, and I think at the moment it adds no value, and I think a lot of that is you hear all these things about a positive mental attitude and if you've got cancer you have to stay positive and the body will repair itself to an extent if you can do the right things and think the right way and I've very much thought actually all this emotion isn't adding any value and so I try... but I don't know if it's necessarily particularly healthy for me, if I'm honest, but it's almost like 'if I start I don't know that I'll stop' and I think that's what's frightening. Recently I had my chemo and it ran late and when I got home I started crying and crying and [my husband] must have thought that I'd had bad news but I said 'no, this isn't emotional crying, it's physical, I'm so exhausted' and it seemed that the only way to get past that exhaustion was to cry and so I sobbed for 45 minutes and then went to bed and slept and I did think at the time I was aware that there wasn't really any emotion attached to the crying, I'm so tired, my body is so exhausted, my mind tired, that actually this is just a physical outlet almost, and so once I kind of acknowledged that I wasn't so concerned, so I think there's the crying that is almost the physical side and then there's the emotional crying which I do think I've really stepped away from since my diagnosis

I: It sounds like the crying felt healing

P: Yes

I: Attached to an emotion, a physical stress

P: Very much how I was feeling about my body rather than how I was feeling emotionally. I was so tired. But I listened to that, I had my cry and I went to bed and I went to sleep and I slept through to the morning. But emotionally, I think that the emotions that come with my illness and how I feel about it are too overwhelming so I've had to keep a lid on it. It's almost like grieving before the need to grieve, it's almost like grieving for something that hasn't happened yet, for something that's lost, from the body point of view, everything that I thought I knew about myself I kind of lost and you know there is a grief that I'm not the person that I thought I was, my life isn't how it was, then there's that grief and that fear for the loss of your life, it's not just about your body not working so much, your existence, I've always very much been one of these that if you offered me eternal life I'd probably take it because I'd like to know what was going on in the world, being aware of your mortality is very difficult, it is something that most of us normally park, you don't need to think about it every day to suddenly realises that you know this body isn't going to keep me going for ever is another scary thing, things you wouldn't have to think about too closely you now have to face. And I think as well, because of my age, it feels sort of out of place, as you get older you expect your body to not do all the same things, there are some things that pass, and for women it's probably their biological clock and all those kind of things, but then you see it further down the line but for me it's like it's all been brought forward, my body has aged before its time, some of this issues that you would naturally adapt to over time, that you're not as mobile and things like that, is brought centre stage, and instead of having time to adjust, one of the things you don't get with this is a lot of time to adjust, because you

are where you are, in a year I went from being fit, healthy, full time job, very on top of things, or so I thought, to suddenly having this body that doesn't do what I want it to do anymore and a year doesn't seem very long, whereas as you grow older, from 40 to 50 to 60, there's that natural adjustment and it's happened so quickly.

I: I think that one of the many things I've been struck by today is the pace of the adjustments that you have had to make, in many different sense, I guess it's body image, it's what your body can do, it's emotional, a lot of adjustment, and the pace emotionally, mentally, you must have to run to keep up with that adjustment

P: It's a bit tiring. It's quite strange really. One of the things they never picked up in hospital, the doctor kind of sat on the edge of my bed and he said "bad luck it's spread and you'll have to have a hysterectomy" and for a woman that's quite a big thing to be told, now that wasn't such a big deal to me as I'm older and children probably weren't going to happen for me and my husband

I: And the way that he spoke with you...

P: He wasn't nasty, he was polite, but I would have hoped there would be some questions about how I felt about that, because it is a big thing for any woman. But then my doctor said to me 'there you go xxxx, you'll never know what's making you feel bad, it could be the change, it could be the cancer, it could be the chemo,' so all these things being on top of that I would have hoped for a bit more awareness, so for me being told that I couldn't have children maybe not the same issues if I had been ten years younger.

I: Another big adjustment, a self adjustment perhaps?

P: I'd kind of forgotten about that, because it was an aside for me. I remember at the time thinking 'my god, how thoughtless' saying you need a hysterectomy without asking 'have you got children, how do you feel', I mean I understand the logic, I had to have a hysterectomy or I would die, so it was a no brainer but at the time it wasn't a big issue for me but I did think that for many women that would be the most devastating news you could give them. But then my GP said to me, 'your poor body isn't going to know whether it's coming or going because they've taken everything away then you're going to have this, you're going to have that and you won't know what's causing what.' I'd forgotten about that. I don't know what you said that reminded me of that, but a major impact on my body and very much dismissed at the time as 'oh, there you go' thing

I: So you've had to catch that one yourself, as you weren't given the space to adjust, it was kind of whoosh!

P: Yes, it was 'and in a couple of hours it will be done' kind of thing, so I knew we were on a tight schedule, I knew things had gone badly wrong because my tumour had ruptured, so there wasn't a lot of space, but I didn't fully understand the impact that would have on my body. So sometimes I suppose that I don't know what's going on with my body and I try not to spend too much time thinking about it, whether the hot flushes are due to the menopause or the chemo then who cares really it just is, and you just have to get on

I: Ok, I've maybe two more questions. The first is about when you talk to a doctor or to your husband and what that's like, you talked about the bag and around issues of

privacy in your conversations with people, but more generally how is it talking about your symptoms with others?

P: Well, I think probably in life really you play different role for different people, and I think that very much effects what you say and how you say, so obviously with doctors and nurses very much more business like from my point of view, and I seem to have the ability to be quite cheerful, one of the nurses said 'oh you're one of our favourites xxxx, you always come in smiling' I'm very much I can put a face on, they'll talk about things and give me my results, and I think I've got a lot better at saying how I'm feeling, cos like you said, at first it's a bit of a muddle and you're not quite sure, so again it is almost getting back I touch with your body a little bit and recognising what's what and not being quite confused about things so I think from that point of view, then there's my friends were, well, I have certain friends were I'm very, very lucky where I will openly share my anxieties with and they're probably be the people where I'm openly my most naked and my most honest, and most tearful and I'll say my fears out loud and then there's [my husband], and there's protection there very much and we'll talk about the fact that I'm tired, so when it comes to symptoms or how I'm feeling I'll tell him when I'm tired or if I'm a bit tearful, it's him understanding that I perhaps don't know the reason for it and he's got much better at reading that and as he's got better at reading that it's actually got easier for me not to get so moody or difficult because I don't feel I'm having to explain it. Because sometimes you can't take out of your head how you're feeling, you know your body isn't feeling right but it's really difficult to pin point, you just know you don't feel well, so he's got better at reading that, so with my symptoms and talking about them there are definitely roles I play and how much information I give and also how much vulnerability I show, I think [my husband and I] have definitely found more even ground, I'm more accepting that I'm tired and he seems to manage the right questions now without me feeling interrogated, because you have to talk about your body a lot now and you actually think 'oh for godsake I don't know how I feel' and there is that sense that you do it all with the doctors and you don't necessarily want to do it all with your friends

I: My final question may strike you as odd! For some people it makes sense, for some it doesn't really, but one of my supervisors has sometime had conversations with people about their relationship with their cancer or with their tumour and some people kind of have a metaphorical or imagery based sense of that and some people don't, what's that like for you

P: Well, it would be safe to say we're not on good terms. As I said to you before, I do a bit of visualisation sometimes and that helps, I think for me... [pauses thinks] do I have a relationship with my cancer, well, we're not on speaking terms at all, it isn't something like that, some people grow to love things about their body don't they, it isn't like that, I'm not prepared to do that, but for me, what I spend time doing is I will visualise it almost and I will drive it out mentally, and I will spend some time... I'm not OCD, if you saw my house you'd know that, but I have certain little rituals sometimes now, and I've always had them, a little bit of good luck stuff and there are certain things I will do and I will run through in my mind and it's sort of 'if I do this then I will have power over my cancer almost', it will either not grow or it will get smaller and go away, now it probably won't do a bloody thing, let's be honest, but I think 'what have I got to lose', so like before it's having this focus and being positive about it so, when I said to you before about owning my body almost,

I'm not really prepared to own my cancer, I see that as completely alien, something that's chosen to attack me and so I will go on the attack back, and I will run through these things and think if I can almost drive it away. Does that answer it for you?

I: Very much so. Thank you. Now question wise that's us done. We'll talk for a couple more minutes just as us but I'll turn the recorder off first.

[Interview comes to an end.]

**Appendix I: Table Depicting Audit Trail of Data Analysis**

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
<b>The Changed Body</b>	<b><i>Frustration and distress at changes in the bodies capacity to perform</i></b>	~ the body doesn't function as well as it did a short time ago	<i>"I mean a lot of things become a challenge now that you wouldn't have believed, or I wouldn't have believed, 18 months ago. You know. But this is what it does for you I suppose."</i>	2	7	13
		~ the body was very fit, physical activity was part of life	<i>"I think the obvious thing is the things that I used to be able to do, that I now can not do, for example I used to love running, I used to go running about 7 miles per day, 6 days per week, took part in Portsmouth half marathon on numerous occasions, the great south run every year [Laughs] and now I can't do that"</i>	1	5	16
		~ This has changed				
		~ Can't do the same things	<i>"... it's just I cannot do the things now that I would like to do or should be doing. You know, I've got decorating to do. Various jobs that I have to do or would like to do but can't do them now because I can't climb ladders, I can't stand around for too long, I can't walk very far, without the aid of... and I mean there's a lot of jobs you can't do without sticks. It's changed..."</i>	2	6	28
		~ Wishes he could be getting on with things	<i>I: Is that frustrating?</i>  <i>"It is a frustration, yes. Especially things like putting your socks on, I mean it's a simple every day thing and it's something that you can't do."</i>			
		~ Feels frustrated				
		~ sex was important to his relationship	<i>"we had a fantastic sexual relationship, which was going to be no more, so as far as I was concerned ... as far as she was concerned I was dead meat"</i>	1	6	29
		~ This is a significant loss				
		~ Changes in the body's capacity are depressing	<i>"it's depressing really in some ways because you can think to yourself 'oh, I used to do that, oh, I won't be able to do that', I don't know really, but it's depressing really"</i>	6	4	4
		~ The body was dependable	<i>"[My body] was always capable, up to that point, of doing what I asked of it. It can now no longer fill that function totally, I mean, yes, it's still keeping me alive and breathing and sleeping and doin' everything else that I do but not as well as it used to"</i>	10	7	15
		~ It still does the things it has to do				
		~ but not as well, imperfectly				

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ Changes in the body's capacity has been one of the hardest aspects of disease	<i>"one of the hardest things has been finding that your body just doesn't do what it used to do and having to manage your expectations, so you know, big things like exercise are one thing, I stopped going to the gym because I had the dogs, but I used to be a real gym freak, I loved to exercise, I've done the London marathon, I've done some quite major health and fitness kind of things and then you go to the other extreme and suddenly you can't do that anymore, even bending down or getting upstairs, all those kind of things are taken away, and that's particularly, very frustrating"</i>	11	7	36
		~ the body has degenerated as if it were aging at a very accelerated pace	<i>"my body has aged before its time, some of this issues that you would naturally adapt to over time, that your not as mobile and things like that, is brought centre stage, and instead of having time to adjust, one of the things you don't get with this is a lot of time to adjust, because you are where you are, in a year I went from being fit, healthy, full time job, very on top of things, or so I thought, to suddenly having this body that doesn't do what I want it to do anymore and a year doesn't seem very long, whereas as you grow older, from 40 to 50 to 60, there's that natural adjustment and it's happened so quickly"</i>	11	10	18

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
	<i>Relationship with the body becomes more explicit as a consequence of disease,</i>	~ no explicit relationship to the body existed previously	<i>"I don't really think I gave it an awful lot of thought, all the time I was able to do things, go swimming, go on the bike, go walking, I think all the time you are alright ... you just get on with things really."</i>	6	6	30
	<i>previously the body has been taken for granted as dependable</i>	~ no explicit relationship to the body existed previously ~ belief that it couldn't happen to her	<i>"up until I had the diagnosis really I didn't take a lot of notice about my body. It happened to somebody else, it doesn't happen to you. And so when it comes it is a bit of a blow and it changes your outlook"</i>	8	1	6
		~ no explicit relationship to the body existed previously	<i>"I took so much for granted because it was just there and you know, now I've got so many things wrong with me..."</i>	8	7	7
		~ no explicit relationship to the body existed previously	<i>"after all those years of um, not thinking about my body in a way, it was always just fit and never let me down and now I feel it has..."</i>	3	1	12
		~ no explicit relationship to the body existed previously	<i>"I was no great athlete or anything but it always carried me through a job or whatever it was I was doing, I had no reason to question it really until the cancer"</i>	10	7	21
		~ felt ok about body previously, was complacent	<i>"I think probably before my illness I had quite a healthy relationship with my body and if anything I was probably a little bit complacent for want of a better word, I've always been reasonably healthy, I've always been reasonably happy with my body image, so probably it wasn't something I gave a lot of time to thinking about particularly"</i>	11	1	5
		~ no explicit relationship to the body existed previously	<i>"I'd never thought about my body before, it was just kind of there and I mean I get up in the morning and I look in the mirror and I think 'Oh! You've aged' [Laughs] Brush my hair and that's it, I didn't bother with the body again, my body hasn't been a big thing in my life until now"</i>	5	1	7

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
	<i>The lived-body is no longer experienced as predictable</i>	<ul style="list-style-type: none"> <li>~ falling asleep due to fatigue</li> <li>~ experienced as intensely frightening</li> <li>~ fear is partly based in the lack of control he feels... he can't even keep himself awake in public</li> </ul>	<p><i>"I went out a couple of weeks ago to xxxx, there's a coffee shop I sort of go in there and whilst it's not self service they'll say, 'oh go and sit over there and we'll bring it over', so fine, so I go and sit down at the table and how long does it take to pour a cup of coffee and take it down a few yards to me and I was asleep! And she said "here you are" and I woke up with a start, I was definitely asleep... it certainly wasn't a deliberate power nap, but I was asleep and she woke me up and she apologised. And I thought afterwards, my god!"</i></p> <p><i>I: That sounds like it was perhaps a bit frightening</i></p> <p><i>"Yes, very frightening."</i></p>	1	10	22
		<ul style="list-style-type: none"> <li>~ he feels vulnerable, this is frightening</li> </ul>	<p><i>"Well, this is it, who knows what's going to happen to you if you fall asleep on a bench in the middle of xxxx. [Laughs] [Sighs] Yeah that is very, very... I find that very, very frightening. And it is getting worse. It is getting worse."</i></p>	1	11	12
		<ul style="list-style-type: none"> <li>~ her stomach might make noises at any time</li> <li>~ she worries that other people might hear</li> <li>~ at the day centre no body pays attention</li> <li>~ she feels she should be ok with the sounds as she shouldn't have to feel embarrassed</li> </ul>	<p><i>I: Are there other ways in which your experience of your body has changed?</i></p> <p><i>"Embarrassment. Because I've got pancreatic cancer, my stomach gurgles a lot and you're sitting somewhere and you can hear [makes the gurgling sounds] off it goes, you know. It's so comfortable here [indicating time at the hospice day centre] because no body takes any notice here but it does make me aware that if I go anywhere, I said to [my husband] if we go to a show and there was a quiet patch and there's me sitting in an audience and off it rumbled, so, that and wind, those are the two things that I'm embarrassed about. But I shouldn't be, it's part of my illness."</i></p>	5	3	35
		<ul style="list-style-type: none"> <li>~ a greater awareness of the body, particularly about what to eat and what the consequences of types of food will be</li> </ul>	<p><i>I'm more aware, I suppose, of my body then. 'Should I eat that or will it make my stomach start off' and so on, you know, 'can I pass that wind without making a noise' [laughs] and things like that, but I haven't gone out a lot, ... it's like going out for a meal for the first time, I haven't done that yet. It's what I'll think sitting in the restaurant 'is the stomach going to start rumbling' [laughs]</i></p>	5	5	8

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ the body has always healed until now ~ this belief is now shattered	<i>"my body has always got better when I've been ill in any form, flu or whatever, a few days and I'll get better and I thought that's what would happen, that my body would heal itself."</i>	9	2	20
		~ once upon a time if I did 'x', my body would respond with 'y' ~ this equation no longer stands ~ this is very frightening and has caused me to lose confidence	<i>"if I had a headache and I took an aspirin then I knew that the aspirin would work and my headache would go, so I could control it, if I felt a bit sluggish, I knew that if I went for a brisk walk I'd come back and I'd feel a lot better, my body would favour me sort of thing, but this frightened me so much that I lost confidence, I couldn't talk to anybody about it, it was really dreadful"</i>	9	2	26
		~ the body was predictable, cause and effect no longer feel obvious	<i>"I sort of relied on my body to heal itself and it usually did [laughs] this is why it's so bewildering when it doesn't now"</i>	9	4	19
		~ it feels like a loss of control ~ the body won't do what it's told ~ you can't be sure what will happen	<i>"I think that there's that thing that you've lost control, probably because I'm a bit of a control freak! But you can't necessarily make your body do the things that you want it to all the time. So very much, if you've got a headache you can keep functioning, you take something for it and you kind of know what the results going to be... yeah, there is that little bit of loss of control, you can't quite make it do what you want it to do, when you want it to do it. It's not as simple as taking a tablet, it's kinda got away from you a little bit, you can't manage the circumstances around your body quite so much perhaps"</i>	11	2	25
		~ something like diarrhoea has become a big issue when it never used to be	Participant is talking about the experience of having a colostomy bag:  <i>"getting used to managing it and changing it and obviously its not as simple as just getting a bit of an upset stomach"</i>	11	3	29

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		<ul style="list-style-type: none"> <li>~ in the past she could relax and indulge</li> <li>~ now she has to weigh up the cost/benefits of situations</li> <li>~ if she's at home she can relax more as she can manage things in privacy more easily</li> </ul>	<p>The same participant discusses the impact of the cancer and colostomy bag on her eating habits:</p> <p><i>"[I don't] want it to upset my stomach, not so bad again if I'm at home by myself. I'll deal with it, if you're out with people, again, it's this little thing in the back of your mind that ticks away, that you wouldn't have to give a thought to before, you'd go out and think 'I'm going to have a night on the drink and the food and if I feel a bit rough tomorrow it doesn't matter', now the consequences are wider, more obvious, need more management, so it's all those kind of things which, again, you wouldn't have thought about before, which you suddenly think 'if I put this into my body what's the impact? How will I manage it? When do I draw my line really?'"</i></p>	11	6	16

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
Changes in self-concept as a consequence of the changed body	<i>The changed body as unrepresentative of the 'self'</i>	~ feels shocked that the body he has now is the same body he remembers in his youth	<i>"When I was in my 30's and late 20's, in those days, particularly my late 20's, in the marine engineering field many things were still done up with big sledge hammers, and my Mum had to tailor my short sleeve t-shirts because my biceps wouldn't fit... and that's what really gets me because when you look at the body now you think to yourself 'Christ, where has all that muscle gone' and all that weight gone. My wife feels the same, she says 'you've got no bum anymore!' and all those things. And that is a piece of it that comes with this thing."</i>	4	3	33
		~ His wife's feelings echo his				
		~ when talking to her GP about her symptoms she sometimes feels very lost, as if she can't remember who she is anymore and what is the 'real her'	when asked about the experience of describing symptoms/body experiences to her GP, the participant said:  <i>"sometimes I think, well, my maiden name was ####, and I say to him 'will the real #### #### please stand up', because I've forgotten who I am, you know, and when I get that, that's when everything comes in on top of me as if I'm not there as a person, I don't know myself, I don't always like myself, it's strange really, it's a strange process"</i>	8	5	32
		~ the hairloss was traumatic	<i>"I said at the very beginning when I had chemotherapy that I didn't want one that would make me lose my hair because it's part of my identity and I felt very let down when this last chemo that I was on, the Oncologist said that my hair would thin but should be alright, but it isn't, I've lost it in huge clumps and that is, was, part of me. It's not like losing a limb, that would be ridiculous to say, but it has had that impact on me, I've lost part of my identity"</i>	9	8	3
		~ it felt like losing an aspect of her self that defined her				

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ looking in the mirror he doesn't recognise his reflection, it doesn't represent the person he was/feels he is inside	<p>Participant is talking about the weight he has put on due to steroid treatment and disease:</p> <p><i>"I don't like that, I mean I walk past the mirror or I look in the mirror in the morning when I get up, I mean it doesn't look like me, I mean I could show you some photos that were taken a couple of years before I was diagnosed and you wouldn't even recognise me, I mean I have actually spoken to people in the supermarket who have worked with me for years and they don't recognise me. So, it's altered my body image in that way, I mean I've never been a body beautiful, I have to say that, but I don't like being this sort of Michelin Man"</i></p> <p><i>I: Right, so it sounds like looking in the mirror, it doesn't match your picture of who you are?</i></p> <p><i>"Well, yeah, my picture is how I was two years ago, you know, and when I look in the mirror now it's a bit of a shock"</i></p>	10	7	4
		~ she wants her husband to still be able to see her as his 'attractive partner' ~ she feels that the colostomy bag changes her ability to be 'the attractive partner' ~ she has to hide the change in order to feel more herself	<i>"there is also my relationship with [my husband], where you know, I still want him to see me as his wife, his attractive partner, and the bag really is a barrier to that, very much so, so I think from a body image point of view that was really, really, difficult. And to start with as well the scars were an issue, because I've got a massive scar from my operation, ... I was literally opened from the chest bone down to the naval, the scar is huge, and I got past that a little bit and my friend showed me her scars from having a caesarean, so I could kind of manage that, you can kind of cover it, it's more manageable, but certainly the bag was a problem for me very, very much so, and is probably even one of the toughest things"</i>	11	3	31
		~ changes to the body have undermined her certainty about her self	<i>"from the body point of view, everything that I thought I knew about myself I kind of lost and you know there is a grief that I'm not the person that I thought I was"</i>	11	10	7

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
	<i>Changes in social role (due to diminished physical capacity)</i>	~ her capacity to care for others has been an important feature of her self	<i>"I've always been a carer person, like, my Mum's still alive and I've always looked after her and now she's having to help me, although we do pretty well together, that I get really fed up about, because I always rely so much on my Mum, and I worry about that a bit, that I will let her down. In some ways that keeps me going because I won't let her down."</i>	3	7	4
		~ the changes in her capacity to do this have impacted upon her sense of who she is	<i>"I've always been a carer, all my life, and when I first went to the block I was younger, fitter and I was able to do more, now I have to sit back and let somebody else do it, but I'll still try and do what I can and that, in doing that it makes me aware of myself but it makes me aware of other people's problems to, and I think in having cancer it does give you a totally different outlook on everything, not just on the cancer but on living and how you behave with one another, you know"</i>	8	7	18
<i>Fear of the body's future state</i>	<i>Fear of the physical experience of death (i.e. suffering at the end) – voiced alongside the statement that death itself (that is: the existential prospect of being dead) is not frightening</i>	~ death itself is not frightening	<i>"I am not scared to die. My biggest fear in all this is for my family and my relations. Personally, bad luck on me, it wasn't quite the plan, and that is as simple as that. But what I also... I do not wish to linger, I do not wish pain and to be, you know, sort of hanging around forever and figuring out if you're going to die or not. That to me, a slow death, would be absolutely a nightmare"</i>	4	3	1
		~ the pain (perhaps the unboudedness) that might accompany death is very frightening	<i>"... dying doesn't worry me at all, how I may die is a totally different thing"</i>	8	1	9
		~ as above	<i>"I'm not frightened of dying, maybe the method of dying is a bit worrying but as far as dying is concerned I'm not that worried"</i>	10	1	15

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
	<p><b>“What next?”</b></p> <p><b>General fear of the body’s unknown future (not specifically relating to the physical experience of dying)</b></p>	~ Voicing general fears around: ‘What happens next?’ ‘When will it happen?’ ‘How will it happen?’	<i>“The thing that worries me more than anything else, which is a funny thing really when you sort of think about it, is ‘what happens next?’ You know, what am I going to experience next? How is it going to affect me? That is the thing that tends to worry me more than anything else... What is going to happen, say, in the future? How far in the future... well, no one knows, but obviously something is going to happen. I’m not going to be able to do this, I’m not going to be able to do that. Is it going to affect me, which way is it going to affect me? That is the thing that tends to worry me more than anything else, you know, is what is the next step?”</i>	2	7	28
		~ Wanting to ask the medics: ‘what will happen next?’ ~ Uncertainty about how it will end/how dying will happen	<i>“You know, as I said, that is one of the things that I wanted to ask the doctor: what is the next situation that I come into? “I: Is that something you have asked the doctors? “Yeah, and they... there’s no answer. I just carry on as I am and gradually will I go down hill? Will I? I mean do all cancer patients end up in the hospice? I don’t know. I sometimes feel, when I come into here, am I going to end my days eventually in here or in a place like this?”</i>	2	13	30
		~ again, death itself is not frightening, but the fear of what might happen to the body, what the body might experience	<i>“Fear is the biggest emotion I’ve had and it’s not the fear of dying it’s the fear of the unknown, of what is to come, and I think that is the thing that I have felt the most throughout all this emotionally is fear; and again that’s what coming here [to the day centre] has helped me with, because [whispers:] you know it’s not going to be nice and there’s going to be days when you might be in pain until they can get the medication sorted, so fear is the emotion I have felt the most”</i>	5	9	13

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		<ul style="list-style-type: none"> <li>~ the future of the body is very frightening</li> <li>~ these thoughts might not often be said but they sit at the back of the mind</li> </ul>	<p><i>"there is very much a fear of the future, if you look at it, so what about if I can't do that in the future, if your body does start to fail, so your pain gets worse, your condition gets worse, you're less able, less able to manage things, less mobile, so I think that a lot of this, and again this is one of those things which is 'over there a little bit' – I don't go too close to it, but there is that almost fear that at some time my body may break down even more on me, and I really don't know how I'll manage that, I kind of manage it now because I see it very much as a step forward and I hope to maintain my current condition, stay as well as I can, but there is that concern, and you see it obviously with other patients, it's very difficult to ignore, at some point peoples bodies break down on them ... I'll be less able, there'll be pain management that I'm not having to deal with at the moment. I think a lot of this you manage because you have to, to live your life, but there is that danger, it does give you some food for thought, how will you deal with that, that's why I kind of park it, but if I'm honest there's that little bit that sort of ticks away back here and if I'm particularly unwell and particularly unable to do things then that's when the fear can really kind of start and the thought that at some point I really won't have control over my body and I won't be able to do what I want to do and with that comes lots of other issues and that's when I keep it at a distance because it is very frightening"</i></p>	11	8	29

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
<p><i>Anxiety/Rumination about the meanings of recent/current bodily-sensatory-experiences</i></p> <p><i>(i.e. unhelpfully 'listening to the body' - see below under 'adaptation' for helpfully 'listening to the body')</i></p>	~ every ache in the body might mean something else has started to happen	"I've got to be a lot more weary about things. Before if I had a knock or I had a bruise or I had an ache, it didn't bother me. But it does now, in that I tend to relate it to, well, is it anything to do with my illness? So that tends to make me feel that something might be, well, that there is a change somewhere in the body."	2	3	28	
	~ Wants to know what sensations mean but is afraid to ask	"I tend to think that [any slight body discomfort] could be related to [the cancer] and I tend to want to know an answer.. If I get a back ache now the first thing that comes in to my mind is 'is it to do with cancer?', because it has spread to my spine, one of the places that it's gone to, it's gone to my ribs, so if I get any pains around the body area 'is it something to do with that?' It's also gone to the other leg, um, is that something to do with it, is it my other hip going? Or is it to do with?... you know that's the sort of things that go through my mind. Before it was just 'oh, another ache, another paracetamol'"	2	3	3	
	~ find her self wondering what might be normal signs of aging and what might be disease	"The other symptoms you get, I haven't quite made up my mind as to whether it's just getting older, well,... I've got a few aches and pains, well, not so much pains as discomfort, all across the stomach and like this, and you also get other funny little things, other discomforts, and one thing that happens is that you think 'oh god, am I going to spend the rest of the days that I've got feeling uncomfortable, am I going to? Is this old age? What is it? Has something gone wrong inside?'"	4	5	10	
	~ recognises that any unusual bodily experiences frighten her ~ fear of the unknown	"I had a pain for four days and you immediately, your mind starts buzzing and my grandchildren have got these DS games things and one day my Granddaughter was sitting next to me and she said 'watch this Nanny' and I watched and my eyes went funny and you immediately think 'has it gone to the brain' you know, and it's that fear of the unknown, of things that haven't happened but could happen, but I'm learning to deal with that."	5	6	9	

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ awareness that the disease will progress so wondering what will be the next sign	<i>"you know more is going to come, you know that your symptoms are going to get worse and you're going to get more unwell, so any little thing you're initial thought is 'what is this now' but I think you've just got to learn to take a deep breath and go 'I could have had this anyway' it's not necessarily part of the cancer, and that's how... I'm the calm one at home, which is so funny, I'm the one doing all this and everybody else goes: 'What! You've got a pain!' [Laughs] And I go 'yeah, it's alright, don't worry about it' [laughs]"</i>	5	6	26
		~ having to calm herself when she feels a new sensation in her body	<i>"I've got so many things wrong with me that any one thing could make me feel like I do and I'm never sure whether it's this, that or that that makes me feel how I feel, so it's made me more aware of the other things that are going on in my body, not just the cancer [but] the thing I'm most alert to is that I've got cancer"</i>	8	7	8
		~ Is calm compared to her family	<i>"... and it's weighing up the balance now as to 'is this normal', because I would have got aches and pains at my age or is this because now my body's not as well as it was"</i>	11	2	10
Adaptation	<i>Learning to listen to the body</i>	~ head says yes, but listens to the body and chooses to act on what she hears	<i>"I have found it hard sometimes because I've found my head saying yes and then I sit down and think 'you know you can't do that' and then I've had to phone up and say 'look, you know I'm really sorry my head wants to but I know I can't' and everyone understands. I've always been a person that doesn't let an opportunity go by, but now I have to sometimes"</i>	3	9	20
		~ learning to listen to the body and pace his day	<i>"I think the best way to describe it is you have to figure out how to pace the day and the body and you also have to listen to your body, if you're feeling rotten then maybe you need a bit more, you know you need to have that rest."</i>	4	5	2

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ has always been a believer in just getting on with things but has begun to learn to listen to the body	<i>"well, the thing about aches and pains, again, I'm a great believer in: you get up in the morning, something hurts and you think, well, right, do I need to take this seriously or do I just get on and I'm a great one for working through, even flu and things like that, I would perhaps have a day in bed, but then that would be it, get on, take it sensibly, take it slowly, but just get on with life, and that is, well, I suppose, there [seems to realise something] <b>that</b> is the difference now, since I've been diagnosed I'm listening to my body."</i>	5	1	24
		~ Gives an example of when she chose to listen to her body and knew it was the right thing to do	<i>"It's like yesterday, my husband and I normally go shopping together ... [so] I thought 'oh, I'll go shopping' but then 'no, I really, physically, don't feel like it.' And I said to my husband 'I'm sorry,' because he's an arthritic, so he has trouble, but I said 'I'm going to stay at home and just lay on the bed' and I would never have done that before my diagnosis, I would have gone through it. Now, it's: listen to what my body is saying: do I want to lay down? Do I want to go out in the garden and do some gardening? And that, yes, <b>that</b> is a big change since my diagnosis."</i>	5	2	5

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ describes her processes of learning to listen to her body	<p><i>The same participant talks again about 'listening to the body' (her terminology) in response to an enquiry about her experience of fatigue:</i></p> <p><i>"But that again is when I listen to the body. When I first came out of hospital my husband wouldn't let me do anything around the house but gradually day by day I took more over, like the dusting, but I do now know when to say 'I've done that room, can I do this now? No, I'm not ready for this now, I'll go and lay down', which is something I wouldn't have done before I would have just said 'oh no, I've got to get them both done and then I'll lay down' now, as we've all said here [at the day centre], the dusts still going to be there tomorrow so let it stay. So, yes, fatigue is a big thing but I do listen to my body. Like last night, I thought, my husband was watching a really stupid film, and I thought 'shall I stay up and watch it?' and I was sitting there and I thought 'no, I'm going,' and I said to him 'now, I'm going to bed.' Now, before I would have stayed, I would have forced myself to sit with him and I thought 'no, my body is saying bed, so I'm going to go to bed'. So I have accepted that side of it. I'm quite enjoying it actually [laughs]"</i></p>	5	8	12
		~ has not been aware of the body in the past but has begun to tune in to it more now	<i>"most of the time you're not aware of your body, you know, when something hurts you feel it, but most of the time you don't feel your body particularly, you're too busy with life to even think about it. But unless something is actually hurting we really don't pay that much attention, well, I certainly didn't. You're just getting on doing what you should be doing, so I think I'm very much aware of how things feel now... and so you have to listen and probably look much more closely now as to what is going on as to how you would have done before I think"</i>	11	2	6
		~ finding a balance between doing and not doing = pacing	<i>"it is finding the balance and it's recognising that yes, on some days you'll be able to achieve that and on other days you won't, and again that's quite difficult to accept, and I've got a bit better at it, I do rest now, because the way I look at it is that actually when my body is feeling stronger I will maximise that time when I can, but I have to accept on the other days... "</i>	11	8	13

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
<i>Adapting plans &amp; planning in advance: taking the changed body into account</i>	~ finding new ways to achieve goals and feel alive		<i>"it's like you're pulling the reins of a horse and saying 'hey, you can't do that now.' So I'll find a different way of doing something. For instance, I've always, every year been a skier, I've skied for years and two years ago I couldn't ski because my left side wouldn't respond and I got a bit fed up and I was there for the week anyway, so I decided to paraglide, so I went paragliding instead. So, it's kind of like I get pulled up with the skiing but then I thought of something else to do. So it's a mad thing I think I have. The adrenaline rush was there, if not more"</i>	3	4	11
	~ has to plan simple expeditions carefully		<i>"I now have to think about just going for my groceries or the post office, whereas you wouldn't think about it before, I now have to plan every little journey. And also it tends to be a lot longer, I can't just nip down the shop, it has to be a big thing. So much more planning is needed."</i>	3	6	27
	~ has to think carefully about things like shopping, both in how and when she shops and in what she shops for		<i>One participant talks about buying clothes now that she has a colostomy bag:</i>  <i>"it's all these things that you're having to make adjustments, it's about the fact I don't have a choice about going to a one piece [swimming suit] or buying longer tops or thinking about the thickness of the material, I have to now, so just thinking 'oh, that's pretty', I have to think 'no, I can't wear that anymore' and one of the things that I did during the winter was I packed up a lot of my little summer tops and got rid of them because I knew that come the summer it would be like even more of a slap in the face because I couldn't wear them anymore. So, get rid of them when I'm not going to be wearing them, but again, they're the kinda things that you used to take for granted a little bit. Then you have to look at it with a different pair of eyes almost."</i>	11	4	29

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ this same planning has to be employed on weekends away	<p><i>The same participant gives an example of planning a weekend away:</i></p> <p><i>"so thinking 'have I got enough things that I can cover myself up and if the weather changes' and things perhaps that you would not give a lot of thought to in the past, you perhaps have to think a little bit more. Again, going back to the bag you have to think 'have I got supplies, have I got everything I need in different sizes and where are we going', that's another things that it has an impact on, you almost have to think 'where am I going? Will there be somewhere that if I need to change I can change that I feel secure'. It's not just a loss of control, it's that you can't just go with the flow, you know, there has to be a little bit more planning there, but you do just get into a routine and I'm not as anxious now as I used to be."</i></p>	11	5	17
		~ Feels that it is 'adapt or die'	<p><i>"you do get used to it, you have to adapt. If you don't adapt you die don't you, for goodness sake, so you have to make the adaptations it's just not always a particularly pleasant experience I think it would be safe to say. So, it can be very tiring, it can be very, very tiring."</i></p>	11	5	34
		~ Believe that there are ways to prepare for most situations	<p><i>"It is just finding tricks and techniques just so that it feels normal and I'm not drawing attention to the fact that actually there is an element of anxiety there, I'm having to think about what I'm doing, eating, drinking"</i></p>	11	6	36

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
	<i>Gaining satisfaction from adaptive goals</i>	~ Has made changes to plans and goals and is able to become excited about these things	<i>"I do think that I'm lucky that way, all my life I've adapted very easily to different situations and I've always found that and I think that's mainly why I cope so well, that I can adapt things and find ways round. [I found getting a] wheelchair horrendous but I got my first chair in January, although I haven't used it yet, but then found out about the Dewley trust that take people sailing so I seem to weight off a negative with a positive, so now I'm running up to going sailing on a beautiful tour ship. So, its kind of took me... I was devastated with the wheelchair, just the whole thing, but now I think 'well, that's given me the opportunity to do the sailing so...' I seem to do that a lot... I don't know if that's a good but I'm excited about it, I phoned them up and I felt quite elated about it."</i>	3	4	17
		~ Recognises that goals need to be realistic	<i>"you have to have little goals, you know, nothing to spectacular that you know is asking more of nature than is likely to happen. But you have to have goals that's an aim I can have"</i>	8	3	35

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
A Tug of War: Ownership of the Body	<i>Losing private ownership of the body: Threats to the privacy and boundaries of the body</i>	~ Has experienced so many occasions of her body boundaries being invaded that she just wants to take the space back at times	<i>"There's so much that gets done to your body once you're diagnosed, you know, I have, well, a phobia is the wrong word, but I'm a little bit nervous of needles now, I've had so many things stuck in me, prodded in me, that you almost want to try and reclaim it a little bit, it's like when I go to the hospital for my chemo, it's like pick line in, flush, the old routine and that's absolutely fine, but it's like you want to try and get something back almost because so many things get done to your body it's just sometimes nice to just be you and your body again without everything else that goes on around it"</i>	11	7	10
		~ Feels that people such as chemists will know his business and make judgements about him and not keep confidences	<i>"[I take my prescription] away from the local Chemist in the village, which is too close for comfort and while the likes of yourself and my doctor and the people at [the hospice] have got certain codes of conduct on confidentiality, well, I'm saying no more. So, to get away from being too close at home..."</i>  <i>I: That seems like an important point though, a sense of these being private things for you and it doesn't feel private.</i>  <i>"Put in a prescription for a certain type of drug and they think "oh yeah" I mean they probably know any way because people have been yakking down the village but that's not the issue."</i>	1	10	6
		~ Feels the loss of privacy	<i>"All your life they've been private things you've done your self then all of a sudden you find you need help to do all these things."</i>	2	6	1
		~ Feels that people don't always keep the things private that they say they will	<i>"people they say 'oh, I won't say nothing to nobody' but you know when they get out of the house they're going to be first down the road telling everybody, so you don't confide in them. And then you get that person who's got that little bit of something and you know that with that person you're safe."</i>	8	4	18

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ Finds that having her actual waste products external to her and having to have this cared for medically is very uncomfortable	<i>One participant discusses managing her colostomy bag:</i>  <i>"I think the fact that it is a waste product as well so you know, something that would normally be very private and very personal, your having to discuss it with the world almost and doctors and getting used to managing it and changing it... and all those kind of things that would normally be really, really private, you're suddenly having to have all those conversations with people"</i>	11	3	27
		~ showing stoma to partner is unthinkable	<i>"The thing is, as well, for him it isn't a problem, it really isn't, and although I've never shown him, because the nurse wanted me to actually show him the stoma, so the opening into my actual intestine but I thought: 'oh! You're havin' a laugh! It's never gonna happen' I don't want him to see the bag, so he's certainly not seeing that"</i>	11	4	7

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
	<i>Who knows best? Compromising informed choice and ownership of the body</i>	~ feels doctors can be pushy and take charge if you're not careful	<i>"The doctors are wonderful and I can't speak highly enough of them but they can tend to intimidate a bit and also I feel that if you don't speak your mind then you will end up being whipped along with something that you're not happy with"</i>	3	9	8
		~ felt that hospital staff were not direct despite his asking for directness ~ discovered that unknown to him he had actually been given a treatment ~ Indicated that without his consent this was a violation	<i>"[At a certain hospital I found that they] hedged around [the issues] and I said 'for Christ sake will somebody tell me what the hell is going on around here' and they suddenly said 'oh we're going to do this' and I went in for day surgery and then I got told I was having something different and I said 'what are you all talking about, this doesn't make sense this isn't why I came here' and then it turned out that this was to get biopsies and do this and that... and then [participant sounds incredulous] I found out through a consultant here at #####, that they had actually given me some chemo straight into the secondaries and I said 'no one even told me, I never signed a consent!' So they were up to their little games, and the one thing at ### was the way they hedged about."</i>	4	7	23
		~ Being treated like an object passed between medics	<i>"your veins get to the stage where they aren't that good, so I got to the stage where they thought I'd be better to have a pick line put in, so one consultant actually said, well, I had the pick line put in, went down and saw the next one and he told me 'oh, you don't need that, I don't think you need that yet' anyway, it ended up with me having it taken out and not having it!"</i>	6	3	16

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ Disempowerment through medics withholding information of the body/disease state	<p><i>"I was quite bewildered, very frightened, annoyed that I wasn't told at the very beginning of my treatment or diagnosis what was happening, it was all sort of smoothed over, in fact the day after I had my operation to remove what the surgeon called 'a mass' by debulking and he came around the next morning and said 'oh, the operation went well' and I thought 'good, everything is obviously ok', and the nurse with him, which I subsequently found out was a Macmillan nurse, gave me a little plastic folder thing with [name of an NHS trust] written on it and said 'oh, I think the things in here will be useful to you' and I thought they were exercise and diet type leaflets and I was still under the anaesthetic and I didn't really take any notice until a couple of days later when I looked and it took about another couple of days for it to sink in what the leaflets were about. Nobody ever said it that 'you have a tumour' or whatever, so I found out by reading these leaflets and thinking 'well, why has she given me that, why have I got that' and realising subsequently that it was cancer but nobody ever said that word or said tumour"</i></p> <p><i>I: The communication with you then...</i></p> <p><i>"... was non-existent"</i></p> <p><i>I: They avoided the word tumour even? And the word Cancer?</i></p> <p><i>"Yes, it was 'mass' and 'debulking' and all these sort of words and not what it really was. If they'd said at the beginning 'well, we've operated, we think we've got rid of everything but there might be some rogue cells but we'll give you a course of chemo just to zap them' or something like that then I would have been prepared, but I wasn't. I was shocked"</i></p>	9	1	11

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
	<b>Retaining ownership (includes making choices about treatment and challenging medics)</b>	<ul style="list-style-type: none"> <li>~ Had to fight to have opinion taken seriously</li> <li>~ Proved entirely right (although right or wrong it was her right to be wrong if she chose)</li> <li>~ Indicates that it takes a force of character to retain this control</li> </ul>	<p><i>"I saw a very nice respiratory doctor, and this was over two years ago, and he wanted to fit me with a feeding tube here and I was having no problems swallowing, eating, drinking, I had the record at xxxx in xxxx for lung capacity, so was feeling quite good and I said jokingly, I can't have that I'm still wearing a bikini and he was horrified! I have to be funny! That is my way around this. And I said, I don't need a feeding tube and he disagreed totally, but two years down the line I still don't need one, and that would have sat there for two years. My neurologist did write to him and say he stereotyped me as a normal 54 year old when in actual fact I was a lot fitter so he should have looked at my notes and seen that."</i></p> <p><i>I: That's quite striking isn't it, I feel glad that you had the ...</i></p> <p><i>" ... the nerve to say no! He wasn't happy with me at all. And I also said, you know, with a bit of research, if he'd have read my notes he'd have seen that my lung capacity was way above normal which is a good indicator and also, I said to him, I saw him the year after, and he was a bit wary and I said 'I have found out that I can have this tube done under local' and he said 'you really wouldn't want that' and I said 'well, if I do (cos that means I can go longer without having it fitted) I'll do it.' So every year I seem to upset this man. But I would have hated that tube being here for two years, being redundant because mentally that's a horrible thing and maybe next year I will need it... and I will know when I need a feeding tube and hopefully, if I haven't upset him too much, he'll do it for me, although it is my prerogative if I don't want one. That is still my choice "</i></p>	3	8	20

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ Had to make strong decision to avoid active treatment that would probably have caused more pain and discomfort in the long term	<i>"in September when they took some biopsies and they said 'well, we could give you a new liver,' and I did a sort of evaluation and it turns out that the anti-rejection drugs in fact suppress the cancer immune system as well and you can end up chasing the damn thing around the body and I thought 'whoa, you're not gonna get me through all that,' and they said 'well, you look fit enough' and I said 'no, you're not doing it, I'm not having it done' and then I said 'well, what do you reckon, what's the chances?' and they said 'well, when we get a liver...' and I said 'no, no, no, we're not playing this game, it's not right to be like this.'</i> <i>So, anyway, the next thing was they were saying, 'well, there's chemotherapy and ...' and I turned around and said 'you're all assuming an awful amount' and they said 'what do you mean?' and I said 'I haven't even consented to chemotherapy' and I then actually told them 'you will have to prove to me that it is beneficial, because if you think that you're going to give me 15 months feeling rotten, or if I'm going to get 12 months feeling alright, you can forget your 15 months feeling rotten because I don't want to know"</i>	4	5	26
		~ States her strong feelings about owning her experience, but does so defensively as she feels challenged on this	<i>I feel very much that this is mine. I own it. So, again, a lot of it is the privacy, and maybe if it was something different I wouldn't feel it quite the same way, very much everything is around people looking at me and almost not seeing the fact that I've been ill or that I've got cancer, but certainly with the bag just not being aware that I'm wearing one, I think that's mine, I own it, I'm not quite prepared to share it almost, it's mine to deal with,</i>	11	7	19

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
	<b>Sharing the body's space</b>	~ Shares an example of being open with the family and choosing to share her body in a way that normalises it for her and her family	<p><i>"I'm quite proud of my girls and my grandchildren. It's like last week, I've got to have [an injection] every day for blood thinning and the grandchildren have heard me say 'Granddad has got to give me an injection, go in the other room' and this week they were with me and I said to my Grandson, 'oh, granddad has got to give me my jab' and he looked at me and I said 'did you want to see it' and he looked at me and he went 'yes!' [emphasising excited tone of a child] he's seven years old and he ran into his sister who is nine and said 'Nannies having her jab and we can watch, do you wanna come?!!' [laughs] and those little... that's how we're trying to do it as a family, to not make it look and feel frightening for them, let them be involved in the whole thing and it's working very, very well."</i></p> <p><i>I: It sounds like it, using a kind of an openness, sometimes I guess things can be kept a bit secret...</i></p> <p><i>"... and I think that can be a bit frightening to a child, I don't want to push them to do things that they don't want to do but if they're comfortable and they want to see something or do something then let's go ahead with it, and it was the look on their faces, because they watched granddad stick the needle in and they immediately looked to my face 'is it hurting', you know, and I was sitting there like that [shows a calm face] and they went 'oh, that reassures them.'</i></p>	5	3	13
		~ Encourages her daughters to remember her body is still her and to engage with it and maintain her dignity for her when she needs them to	<i>"It's like, I said to my daughter the other day, I said 'when the worst comes', she said 'yes Mum, I said 'if I'm lying in bed and there's a few hairs on my chin, you will pull them out won't you' and that's the whole attitude we're trying to keep about it. I want my dignity, I want to look good, I want to look presentable, so don't think you can't touch me ever, at the end, and do things."</i>	5	4	14
		~ Has been able to let her husband closer to the difficult physical experience of having a colostomy bag	<i>"when they said the bag wasn't going anywhere that I had to do something about it, I did have a few conversations and spoke with a nurse at the hospital and kind of brought that barrier back a little bit, that I will discuss it [with my husband], but I would still say that very much he respects my privacy, that when I get ready for bed he wouldn't just walk into the bedroom without knocking, without being sure that I'm ready for him to come in."</i>	11	4	15

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
	<i>Empowering self through self-education &amp; research</i>	<p>~ Research/learning about what is happening has allowed her to feel like she knows her body a little still and understands what it is doing</p> <p>~ Notes that this makes her a 'difficult' patient for her neurologist!</p>	<p><i>"the research then helps because you find out what is happening to the neurons and how it depletes your muscles and you kind of find yourself formulating little plans, and although there's no cure it has made me feel that by pushing myself I am helping myself and without the research, it's a very complex illness, I wouldn't know why it stops the muscles working, why does it stop you speaking."</i></p> <p><i>I: So with the learning, you can understand what your body is doing in a way? It makes more sense to understand what is happening?</i></p> <p><i>"I do find that helpful, I don't think my neurologist and that does because I ask questions and sometimes disagree and they don't like that. But I feel you have that right."</i></p>	3	8	6
		<p>~ Has found reputable internet sites have helped him understand his body and also given him power to understand his options/choices</p>	<p><i>"When I got the primary I went on Cancer backup [an online cancer support site] and looked at it and saw what the alternatives were etc etc, and when the secondary came I went on cancer backup again and I found out various things that I felt I should have been told but I was never told.</i></p> <p><i>I: And it feels that it would have been helpful?</i></p> <p><i>P: I think it would have been helpful because I've said a couple of things here [at the hospice in day care] which has surprised me with this induction we have been doing, where the people have sat next to me and looked at me quite blankly and I've said 'well, they can tell how advanced it is' from bloods and they've said 'oh, they've never said that' and you think 'god, I better shut up' because there is obviously still a lot of not telling with what is going on"</i></p>	4	6	36

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ Has found it difficult to piece together information and has sometime heard conflicting information but recognises that good, accurate information helps him	<p><i>"It's like this, you don't know anything about it until it happens. You can read books, you can read that, but you don't have the hands on experience until it happens to you..."</i></p> <p><i>I: It almost sounds like, it's really interesting, you talked about how you gathered information about cancer and particularly about your cancer and it sounds like you've kind of gathered it partly from talking to other people, um, from the Heath centre, your brother in law, and partly from talking to doctors. And the information you've got has been sometimes a little bit different from both directions and I guess you've then got to try and reconcile it and make sense of it.</i></p> <p><i>"Well when you start getting sort of little different bits of information from there, there and everywhere, it really makes the old mind tick over and unfortunately in some cases it tends to tick over in the wrong direction and you can get sort of false information, which is quite damaging to ones state of mind at that time... I think that the more in contact with this sort of service you can be, the better you will be, the more knowledge you will gather."</i></p>	2	10	3
		~ Feels that know what is happening helps one deal with it and cope with what is	<i>"I've always said, 'I like honesty, I don't like people trying to shield you from things', because what you know you can cope with, it's the unknown that you can't cope with. Once you know it's so much easier, rather than thinking to yourself 'I wonder if it's this, I wonder if it's that' when you know what it is you can say 'well, that's what I've got and I have to learn to live with it"</i>	8	3	21

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
Communicating about the body	<i>Communicating with other palliative patients is normalising</i>	~ Talking with other palliative clients helps him and his wife talk, brings the talk into the open a bit more	<i>"I found that coming to the [day centre] has given both myself and my wife a great bit of encouragement in the fact that we can talk to somebody with relation to our illness, well, my illness, in the [light of] other peoples illnesses."</i>	2	2	16
		~ Comparing notes with another patient helps normalise his experiences	<i>"because there's another patient that comes who is virtually in the same situation as me I believe and he gives me encouragement in the fact that we can talk about it. You know it's not something that I've had to keep bottled up waiting for the day when it all breaks out."</i>	2	3	1
		~ as above	<i>"One of the people I refer to quite often, and I speak to him every day on the phone, that is my brother in law, who as I say, is in the same situation. Are these things affecting him? Does this affect you? Does that affect you? "</i>	2	4	16
		~ Talking to other people about their experiences helped create perspective and alleviated some distress	<i>"... coming here made a great difference to me, cos when you're on your own you've only got yourself and your symptoms, then you come here and you see other people and you think 'they've had four, five lots of chemo and they're still here, they've had the illness for four, five years and they're still here' and as I said to ##### last week 'I'm a learner, I'm on chemo number one and #### is on chemo five or six' and there is so much more she know's then I know and ok, it might not work that way for me, my cancer might be different in that it races ahead, but there are options. When you're first told you think, there's no way out of this... its seeing people like the girls in there and the fellas [indicating the day centre] and you think 'yeah, there are chances, there are options, there are other ways of going 'so...'"</i>  <i>I: So, encountering and being with people who have been on this journey has, for you, been really important</i>  <i>"Yes"</i>  <i>I: and all different experiences but it has been hopeful</i>  <i>"Yes, it has, the initial shock has now worn off and I can see there are... just because one chemo doesn't work, there are others that could possibly work, you know, and I wouldn't have known that if I hadn't talked to the girls... 'the girls!'... 'the seniors!' [laughs]"</i>	5	6	37

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
<i>Communicating with medics as a learned clinical style</i>			<i>"you see you can't talk to people that have no knowledge of what you're going through, they just don't want to know, but the people who have been through it they know what you're talking about, that helps enormously, you don't feel that you are imposing your illness on them because they're going through it themselves, they know"</i>	9	4	33
		~ Feel ok about sharing with people who know about it first hand	<i>"that is one of the nice things about coming here, I know that everybody, although they may not be suffering from exactly the same thing, but are in the same boat"</i>	10	6	15
		~ Looks actively to say things as the medics want them to be said, is not trying to express experiences freely but is carefully considering the audience	<i>my thing was always, when I went to the doctor or anything, I'd always say 'of no, I'm alright, that type of thing, and sort of talk like that, but now I do, I try to tell them exactly, in fact I write things down now because I thought to myself 'well, when you think about it it's only right, I mean they can't know how you are unless you really explain to them'.</i>	6	5	8
		~ acknowledges that words can't always do justice to experiences	<i>"It's not an easy thing to do[ communicating with medics], because so often there doesn't seem to be words that express what you're feeling. I mean my own doctor now I've had him so long that he sort of knows me now like the back of his hand"</i>	8	5	31
		~ Is business like	<i>"when you're talking to doctors and medics you're more business like I suppose,"</i>	9	9	22
		~ acknowledges that words can't always do justice to experiences	<i>"sometimes you can't take out of your head how you're feeling, you know your body isn't feeling right but it's really difficult to pin point, you just know you don't feel well"</i>	11	11	35
		~ acknowledges that she is aware of different roles (or ways of relating to others) in different circumstances, so takes a business like role in medical encounters	<i>"I think probably in life really you play different role for different people, and I think that very much effects what you say and how you say, so obviously with doctors and nurses very much more business like from my point of view, and I seem to have the ability to be quite cheerful at first it's a bit of a muddle and you're not quite sure, so again it is almost getting back I touch with your body a little bit and recognising what's what and not being quite confused about things"</i>	11	11	21

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ Looks actively to say things as the medics want them to be said, is not trying to express experiences freely but is carefully considering the audience	<p><i>"with the doctors because I'm looking for what they're looking for, and I'm thinking 'what do they want from me?' and I try to, and I probably tend to tailor what my answer is to what I think they want to hear. How can I explain it? [It's] not so much what information [I give them] cos I'm quite open about it and I will tell them what I am going through but I try to do it in a way that makes sense medically, I mean, I don't know how other people react, I don't know if the bloke next door to me's got exactly the same as me, whether he suffers the same symptoms or not and how he would describe them, you get headache, what's a headache to you, what's a headache to me. One that might floor me might just be an annoyance to you or him"</i></p> <p><i>I: Yes, I'm sure we do all experience things differently and then we react to them differently, so explaining that to a doctor, does that make it more challenging or...</i></p> <p><i>"I think it does, because I don't want to over dramatise a situation but then I want them to know how I feel as well, so I think you've got a bit of a fine line there between, um, what..."</i></p> <p><i>[Pauses, uncertain]</i></p> <p><i>I: Perhaps you want it to be accurate, you don't want to oversell it or undersell it, you want them to take you seriously as well</i></p> <p><i>"Yeah, I don't want him to think this bloke is making a fuss cos that's not the sort of person I am but I want him to know that I don't feel well or whatever going on with me at that time, because I want him to know what's going on, because if I don't tell him that, if I don't give him the facts reasonably accurately he ain't got a chance to help"</i></p>	10	3	5

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
	<i>Communicating openly with family and friends</i>	~ her children might imagine it is even worse than it is if she doesn't communicate honestly	<i>"I know what's happening to me, my children don't and they imagine. They could be imagining it's worse or they could be imagining it's better, you know, and that's a difficult bit to breach, to get them know that it's unpleasant but it's not necessarily doom and gloom ... it's not easy but if everybody knows the same thing you are all playing from the same rule game aren't you, you know every body is playing to that."</i>	8	3	23
		~ feels that finally have a right to know	<i>The same participant explains that she is open more readily about "physical more than emotional [experience] because I think they have enough emotional stuff to care for in themselves and so do you. But physically, if you feel bad, I think they have a right to know. And mine say I don't make enough fuss, but I don't need to make a fuss because if I don't feel well, I don't feel well, and if I feel ok then I feel ok."</i>	8	4	4
		~ With certain friends shares almost everything	<i>"I have certain friends were I'm very, very lucky where I will openly share my anxieties with and they're probably be the people where I'm openly my most naked and my most honest, and most tearful and I'll say my fears out loud"</i>	11	11	29
	<i>Protecting family</i>	~ Feels he has to protect his wife because she is emotionally vulnerable	<i>"I have to be careful, I mean the subject comes up she goes into a sort of a shell, a bit of depression. She does suffer from depression for a long time so, you know, I mean I've had experience of her depression and I try not to put anymore pressure and that on her"</i>	2	2	9
		~ Plays it down with family	<i>"whereas with the family you try to play it down and perhaps make a joke of different things, keep it light"</i>	9	9	22
		~ Wants to protect husband from emotional impact	<i>"then there's [my husband], and there's protection there very much and we'll talk about the fact that I'm tired, so when it comes to symptoms or how I'm feeling I'll tell him when I'm tired or if I'm a bit tearful"</i>	11	11	31

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
	<i>Friends and family 'play it down' or 'over-react'</i>	~ Feels as if people don't appreciate the difficulties	<i>"sometimes if you get people continuously saying to you 'oh, don't you look well, oh, you look alright' that can get on your nerves... they just don't realise sometimes what you have been through, but then again I suppose you shouldn't expect them to really, I don't know"</i>	6	5	33
		~ Feels as if people either don't appreciate the difficulties or think that he should be dead already	<i>"I found talking to family, friends and neighbours sometimes very difficult, because they do not understand. I've said, and other people here have agreed with me, friends, family, and acquaintances seem to fall into two groups; those that think you got a head cold and those that think that you should really be in your box."</i>	10	5	17
The Body Under Attack	<i>Cancer as an Intruder to the Body</i>	~ Body is ok, battling intruder	<i>"I still consider it a fit body that's dealing with this intruder."</i>	7	2	5
	~ The cancer as intruder	<i>"[The cancer is]an intrusion, yes, it's something nasty, I've got to get rid of this, that sort of thing, I'm fighting it"</i>	9	7	15	
	<i>Medical Treatment Experienced as an Attack on the Body</i>	~ Treatment has a terrible impact, feels like an attack	<i>"your body's ill but it almost seems to take a battering from every side, everything that is done almost seems like an attack, you know it's needles or medication or chemo... you have this surgery, you have the recovery, then it's like 'I want to start getting better now, to start going out, to start doing things' and then they hit you with this next lot and everything starts to feel like it's not working again"</i>	11	7	20

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ Treatment has a terrible impact, feels like an attack	<i>"I went through a stage of having almost like stabbing pains in my legs and your feet go a bit... your toes go a bit funny and I still got a tingling feeling in my toes and that but you know, that stabbing wasn't very nice at all and a lot of people are very sick form the start and I was never, I've only in this last lot of chemo been sick, but I never was before. So, I didn't have that but it does make you feel very tired. And I don't know, sort of run down everywhere and you can sort of feel a bit sick sometimes even if you're not sick, and the awful thing is that some of it is every three weeks and some of it is every four weeks. The one I'm on now is 3 weeks and you know, 3 weeks seems such a short time because you know you just seem to have got over one lot and then you're on to the next lot."</i>	6	2	26
		~ Treatment has a terrible impact, feels like an attack	<i>"I had 2 sessions of chemo, and after each one my PSA reading went up and I was violently ill, I really was ill with it, it was, it's indescribable. I was so ill. And I went back for my third session and before [you have the chemo] you see the consultant and she said "It's not working, I'm not going to give you anymore chemo therapy, sorry." [Pause] YES! It was a victory [ambiguous emotion present]"</i>	1	4	25
		~ Treatment on brother-in-law seemed awful	<i>"the damage that this radiotherapy has done to him makes me feel in a way that I'm pleased that I didn't have to have the amount of radiotherapy that he had. It's burnt him in various places incredibly."</i>	2	2	30

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
Mind/Body Relations	<p><i>The Body's Betrayal</i></p> <p><i>'I treated my body well but it still let me down'</i></p> <p><i>Describes a sense of unfairness that the body is degenerating despite the participant pursuing a healthy life style</i></p> <p><i>Which may have included engaging in exercise and abstaining from unhealthy foods and smoking</i></p>	~ feels that after a positive mind-body experience throughout life, the body has let her down	<i>"I was a ballet dancer and then athlete and then a tennis coach and personal trainer. So my body has always been very important. I kind of feel now that it has let me down a bit"</i>	3	1	10
		~ Feels that she did her part and the body has not lived up to its role	<i>"... if you've looked after something you kind of think it will service you better and then you get slammed with the most horrendous illness which really is awful and you can do nothing about"</i>	3	8	1
		~ Feels disappointed at the body	<i>"Relationship to my body? Um, disappointed is the word I would use... I've tried to be good through out my life, you know from the point of view of not having a lot of indulgences and when I was told the secondary cancer had come I was not surprised but I was disappointed that it had come so early for me, because I'm only nearly 59"</i>	4	1	6
		~ Feels frustrated at the body	<i>"I suppose it's a bit frustrating because as I said I'm a pretty fit person and I guess it's a bit ironical that I see all these other, a lot of other people around abusing their bodies and in pretty bad shape and so, yeah, it's perhaps a bit frustrating that I'm in good shape except for one problem"</i>	7	2	19
		~ Feels explicitly betrayed	<i>"Well, I suppose [that having a relationship with my body means] being in control of my body and I think I feel now that I'm not in control of my body, that my body is betraying me in some way"</i>	9	1	6
		~ Feels as if the body has turned on her	<i>"I suppose I do feel a little let down by my body. It has been a bit of a shock that perhaps I'm not as healthy as I thought I was, I mean you do all the things they say, I've never smoked, I've always kept fit and healthy, I haven't really had any physical illnesses particularly, other than a little bit as a kid, but generally ok, so it has been a little bit of a slap in the face that suddenly my body has decided to almost turn on me a little bit"</i>	11	1	23

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
		~ Felt that after he had treated his body well, the body had let him down	<i>"when I found out I got cancer I thought to myself 'hang on,' I came back here and poured myself a gin and tonic and I thought 'now, this is stupid, here's me going around the supermarket, being very careful of what I eat, because I don't want high cholesterol levels which could kill me and creeping up on the inside is cancer, which is gonna kill me'"</i>	1	5	16
		~ as above	<i>"I think I generally was quite respectful of my body, you think, 'well, come on, I looked after you and this is what you give me in return'"</i>	11	2	29
		~ feels like treating the body well was a waste of opportunity	<i>"I think if you accept that you are going to die, well, I think that perhaps I am a little miffed that I missed out on a lot of things during those years of healthy living"</i>	1	6	11
		~ The body seen as an enemy	<i>"where's it [the body] going to attack next, sort-of-thing, it's becoming a foe or an enemy rather than a friend"</i>	9	8	26
	<i>Losing synchronicity/becoming divided</i>	~ Is frustrated between the division that has emerged between body and mind	<i>Ballet is huge concentration and requires a lot and I did other forms of dance like modern and things that were very fast. Now it feels different because my mind isn't letting me down but my body is, so now it seems, like I said, like they're fighting. And um, I've always been very strong minded and so the gap seems there now</i>  <i>I: There's a gap there now? What's that like the feeling of having a gap between mind and body, when for you, perhaps more than for a lot of people, with ballet you closed that gap, and now its become wider. What's that like?</i>  <i>"Well, the word that comes straight away is frustrating because there's so much I still want to do in my mind but then I have to sit down and say 'hey, you can't really do that now.' So all the time my mind goes that way and my body pulls it back. It's like being pulled up all the time."</i>	3	3	32

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
	<i>Interaction between emotions (mind) and symptom experience (body)</i>	~ Feels they should be better connected and the body should be obeying the mind, but it doesn't happen	<i>"you feel your head should be able to make your body do what it wants your body to do, you know you should be able to make that connection, but actually if you have a thought that you want to do something, and I'm sure that for anyone who has any kind of disability they would laugh at that, but if you've never had a restriction before, my head tells me to walk over there and pick something up and I should be able to do it, but suddenly my body is saying 'no', so some big adjustments there"</i>	11	8	4
		~ A good day can make her symptoms reced a little	<i>"I might walk in here feeling a bit rough but I might walk home feeling a lot better... I think mental and physical both go together. I think if mentally you're lightened it does take pressures off your body I think. You know yourself, if you've got a sore back, if you go out and have a laugh with somebody suddenly you've forgotten your sore back because you're enjoying yourself and that's what coming here does, gives you a sense of enjoyment."</i>	5	7	30
		~ Going out more can make you feel better	<i>"I think, on your bad days you think 'oh, I can't be bothered to do my hair today' and things like that, because I always find that I feel better when I'm out and I've made the effort"</i>	6	5	25
		~ When the cancer and treatment symptoms are less obvious the challenges to emotional coping diminish	<i>"At the moment I'm on chemotherapy that's been working quite well so it's not affecting me much but if you were to ask me when it was affecting, me and I was quite low then I might have a different answer for you"</i>	7	2	25

Over-arching theme	Higher order theme	Clusters of initial themes/interpretations	Participant quote from transcript	Participant ID	Page	Line
	<i>Mind over matter (visualising the cancer)</i>	<p>~ Has a strong belief that the mind can affect the body</p> <p>~ Tries to use the mind to affect the body by visualising the body attacking the cancer</p>	<p><i>"I did a lot of Yoga and I was Yoga instructor and that is a marvellous mind. Mind is a very strong thing. Mind over matter is a very strong feeling. So I feel that helps."</i></p> <p><i>I: And it sounds like that at those times you've visualised, that the tape invites you to visualise the cancer; what's that like?</i></p> <p><i>"Well, I just visualise it as a mass and try to say to my mind 'shrink, dissolve, go away' sort of thing. And it's not. It's not working [laughs] so, that is frustrating, because you think 'my mind will tell it and it should go' and in the past my mind, by taking an aspirin, has told my headache to go away and it's gone and I expect it to happen with the tumour"</i></p> <p><i>I: Kind of willing the body to obey</i></p> <p><i>"Yes, for all the white cells to kill off the black cells and you just expect it to work and of course it doesn't"</i></p>	3 9	10 6	35 5