

INTRODUCTION

This study forms part of my submission for the degree of Doctor in Social Work and develops my interest in exploring the individual experience of living with life-threatening illness.

My interest in this research developed from my practice as a Social Worker in Palliative Care, during which time I became fascinated by the different reactions and responses individuals displayed to a diagnosis of life-threatening illness, and the trajectory of the illness, in particular, in cancer, which did not always result in death. During the time I worked in palliative care, an increasing number of 'patients' were discharged and what interested me particularly was the way in which they managed this process, and the nature of the experience of 'surviving' a potentially life-threatening illness.

This study, which I did not commence until I had left social work practice and entered the field of higher education, is the outcome of my research in this area. The chapters that follow set the context of my research by considering relevant literature, outlining the process and methodology of my research, exploring and analysing the experiences of individual respondents and considering the findings in the light of current policy and practice.

PART ONE

LITERATURE REVIEW

Theorising Dying

According to Holloway (2007, p37) “Death, dying and bereavement have been the subject of considerable interest to scholars since the middle of the twentieth century, despite the message that we are a ‘death-denying’ society. These attempts to define how death is handled in societies and its impact on individuals and communities become ever more complex as one dominant approach supersedes another...A number of disciplines have contributed to this theorising and each makes its own contribution. So, for example, in the early part of the twentieth century, it was social anthropology which turned its attention to the rituals and symbols which societies construct to manage death, first through the examination of primitive societies and then shifting focus to search for patterns in modern society. The degree to which social ritual is present or absent in death has been taken up by sociologists as a key indicator of whether or not death is denied, hidden or open in a given society. The denial of death has been a central tenet in sociologists’ accounts of death in modern western societies.”

The work of sociologists in the study of death, dying and bereavement dates back to the 1960s in the United States, when the first, still influential, empirical observational studies looking at the care of people who were dying were conducted in hospitals (Glaser and Strauss, 1965, 1968; Strauss, 1970). Such research fundamentally changed the way people thought about the management of dying, and brought the experiences of those dying (in this case, in a hospital environment) very much into public awareness.

Studies in Britain have also explored the management of death and dying, both within the acute hospital setting and within the hospice movement (Field, 1989; Seale, 1989; May, 1991). The development of the hospice movement and that of palliative care as a specialism are interesting in this context, as these did much to bring the needs of dying people, and particularly those dying from cancer, to public consciousness. The charismatic work of Dame Cicely Saunders in developing services for people who were dying outwith the mainstream acute hospital setting was formative in establishing a particular framework for the care of people with ‘terminal’ illnesses, and this seemed to many to be above reproach – indeed, the

adage 'do not speak ill of the dead' seemed for many years to apply also the hospice movement. However, the studies of British medical sociologists (mentioned above) sought to challenge some of the taken-for-granted assumptions of palliative care, which, although uncomfortable for many, has at least opened up the debate about what palliative care can and does achieve (Exley, 2004). James and Field (1992), for example, suggested that the provision of palliative care within hospices, far from being individualised and holistic as it purports to be (in contrast to the care provided in the hospital setting) is, in fact, becoming increasingly 'routinised' and bureaucratic as it develops its own mores and standards of care, which could be seen as another way of defining a 'good' death which does not allow for individual choice or preference. Another example is Lawton's (2000) ethnographic study of the care provided within an NHS hospice. This work has been particularly influential in the way in which it has challenged the way in which people who are in receipt of palliative care services are actually viewed. According to Exley (2004, p 113) "The public image of hospices facilitating dignified or 'good' deaths was challenged as she sought to examine what happens when people's bodies fail them in the most socially unacceptable of ways, leaving them devoid of personal identity and unable to engage any longer on any meaningful level with significant others because their physical bodies have failed them so badly."

Managing Dying

According to Holloway (2007 p 115) "Twentieth century developments in the care of people who are dying emerged out of a deep concern about the attitudes and practices prevalent in the western world and entrenched in its hospitals and healthcare systems, and the additional and unnecessary suffering this caused to dying people and their families. Thus the hospice and palliative care movement has been underpinned by a valuing of the individual and has developed a philosophy of care which places their comfort and dignity at the centre. This has led to a natural desire to define those characteristics which make for a 'good death'. However, that which grew out of the transforming influence of the hospice movement has been in danger of turning into the opposite – a restrictive template which pathologises those whose dying does not conform." In common with Holloway, I recognise the need to

understand how 'dying well' means different things to each individual, and that a careful process of negotiation is necessary to ensure that the support given to someone living with a life-threatening illness is personally acceptable and that the social circumstances of the individual are recognised and taken into consideration. Walters refers to this as 'dying with panache', which may include 'raging into the night', if this is how that person has lived their life and would be congruent and authentic in death (Walter, 2004, p 408). In this study I am seeking to discover how possible it is to *live* with panache and to be as 'individual' in facing death as one may have been before life-threatening illness was diagnosed.

Conceptualising Dying

A significant area in the literature on death and dying is the development of theory concerning the processes and course of dying. In 'Time for Dying' (1968), Glaser and Strauss described what they called 'dying trajectories'. In essence, such trajectories are defined by 'duration' (the chronological *time* between the onset of dying and the arrival of death) and 'shape' (the characteristic *course* of the dying process). Illness that have a relatively short dying trajectory tend to move more or less directly to death, while those with a longer, more extended dying trajectory may involve either a fairly consistent decline or one that is more variable and ambiguous. Cancer would, it seems, now fall into the latter category (Corr et al, 1999).

But Glaser and Strauss saw a subjective element in the concept of dying trajectories, since they noted an attempt on the part of professional care providers to predict the course that the disease would follow. In other words, when confronted by an ill person, Glaser and Strauss noted that professionals often make fairly rapid estimations about whether (or not) and how a person may die. They observed that professionals organise their work on the basis of these estimates, and that people who are living with life-threatening illnesses are therefore treated in differentiated ways. Thus dying trajectories involve both disease processes which are peculiar to the individuals who are ill and also important elements of assessment, communication and interaction between dying persons and their care providers.

The role of subjective estimation in dying trajectories was further developed by Pattison (1977) in *The Experience of Dying*. As the book's editor, Pattison brought together more than twenty contributors who described various encounters with life-threatening illness and dying, differentiated both by the underlying causes from which they arose and by the era of the human life span in which they appeared. As Pattison noted, these diverse accounts of dying serve well to reject "Hasty overgeneralisations that are used to draw global conclusions about the dying process" (p1). But Pattison went further. In his own chapters for the book, he sought to frame understandings of dying in terms of what he called the 'living-dying interval' defined as "the period between 'the crisis knowledge of death' and the point of death" (p44). Pattison thought of the living-dying interval as involving a personal trajectory through three clinical phases 1) the acute crisis phase in which an individual first becomes aware that death is likely or imminent 2) the chronic living-dying phase during which an individual may cope in more or less adaptive ways with episodes of illness, the duration and predictability of which may vary greatly and 3) the terminal phase in which death itself comes ever closer and eventually arrives. The point of this three-phase analysis of the living-dying interval is to provide an overarching framework within which wide variations in processes of illness, challenges, concerns and coping can be properly appreciated.

Coping with Dying

A second area of conceptual development in the literature has involved coping with dying, although it has not always been explicitly framed in this language. This focus was evident in the work of Pattison (1977) who, as previously mentioned, deliberately sought to represent many variables in the dying process. These variables included differences associated with temporal and developmental aspects of dying, dissimilarities in expectations about dying, disparate social and familial contexts for dying, diverse ways in which individuals cope with dying, and the many personal ramifications of dying (see also Corr et al, 1999, and Corr et al, 2001).

Perhaps the most widely known, if not always the most carefully understood, work in this area is that of Kubler- Ross (1969), which was written up in her seminal book

On Death and Dying. This approach postulated a sequence of five stages in response to awareness of impending death: denial, anger, bargaining, depression and acceptance. The stages themselves were described in various ways by Kubler-Ross: as ‘reactions’ or ‘responses’, as ‘defence’ mechanisms and as ‘coping’ strategies (Corr et al, 1999). While Kubler-Ross noted that “the one thing that usually persists through all these stages is hope” (p 138), popular attention has focussed mainly on the so-called ‘stages’ and the progress (or otherwise) of an individual through them, and far less on hope and its implications.

Although all stage theories are inherently sequential and directional (one is seen to move forwards or backwards in a process of progression or regression, toward or away from some ‘baseline’), Kubler –Ross herself suggested that dying people and others who were coping with dying could ‘jump around’ from one stage, or psychosocial reaction, to another and that various stages could sometimes exist simultaneously. That tends to undercut the most widespread interpretation of her work which emphasises the intrinsic interconnectedness and linearity inherent in the basic concept of stages.

The fundamental merit of this theoretical framework and what I would see as its most salutary feature is the emphasis placed by Kubler-Ross on the dying individual’s responses to what is happening. With this in mind, Corr (1993) proposed three lessons to be drawn from her work 1) that dying people are *still alive* and may have important things they need or want to do; 2) prospective helpers cannot expect to provide effective care for dying people unless they *actively listen* to such individuals and determine with them the priorities that should govern such care and 3) there is much that all human beings can *learn from* dying people about our common mortality and ways of responding to imminent death.

It would seem that the stage-based theory proposed by Kubler-Ross resonated with the spirit of the times in its rejection of a dehumanising technology and its affirmation of a ‘natural death’ (Klass, 1982). Her theory remains alive in the public mind and in many areas of professional education (Coolican et al, 1994), although it has been firmly rejected by certain well-known scholars (eg Feigenberg, 1980, Kastenbaum, 1998; Pattison, 1977; Shneidman, 1980/1995; Weisman, 1972, 1977).

For example, Weisman (1977, p 121) insisted that ‘schematic stages ...are at best approximations and, at worst, obstacles to individualisation’. Pattison (1977, p 304) noted that “staging dying” may oversimplify coping processes and suppress individuality in coping (Corr et al, 1999).

Weisman (1984) also insisted on the distinction between *defence mechanisms* (which, in his opinion, merely seek to avoid and ‘ward off’ problems) and *coping processes*. As Weisman indicated, coping involves more than an automatic response or a defensive reaction. Coping is, in fact, or at least can be, an active process that seeks to resolve problems or adapt to challenges in living. This draws attention to the possibilities of active adaptation and accommodation in coping with living with life-threatening illness (see Interpretation of Findings, Part Two).

His constructive understanding of coping led Weisman (1972) to confirm the importance of hope in experiences of dying and to advance the concept of an ‘appropriate death’ (as against an ‘appropriated death’). Perhaps unconsciously alluding to Kubler-Ross’ fundamental tenets, Weisman observed that “hope and acceptance of death are basic concepts because they insist that mortality is a dimension of living, not merely a negation or an endpoint that cancels out everything. Hope is, indeed, the basic assumption in living and dying...” (p21).

Working independently, Corr (1992) and Doka (1993) emphasised ways in which dying people cope with the knowledge of their own mortality. Both found *task-centred approaches* to be valuable in understanding the issues that people face as they cope with the awareness of their own impending death. For this, Corr identified four dimensions of task work that need to be included in a holistic account of coping with dying: physical, psychological, social and spiritual. Physical tasks centre on the satisfaction of bodily needs and the minimisation of physical distress; psychological tasks typically emphasize security, autonomy and richness in living; social tasks involve interpersonal attachments to particular individuals and social groups, and spiritual tasks are based on meaningfulness, connectedness, transcendence and hope (Corr, Nabe and Corr, 2000). This would seem to accord with the increasing emphasis on an holistic and multi-disciplinary approach to care for individuals with life-threatening illnesses, incorporating health and social care in equal measure

(Holloway and Smith, 2010, *Supporting People to Live and Die Well*; see Part Three, *Informing Policy and Practice*).

The concept of tasks implies an element of influence which individuals can exert in an effort to manage what is happening to them. This is consistent with recent emphases on task-based models in mourning after a death (Attig, 1991, 1996; Corr and Doka, 1994; Worden, 1991). Task work also provides room for variation in the ways in which individuals choose to focus on the many potential tasks that may confront them at any given time, and how they may address the tasks that they select for emphasis.

Doka (1993) extended this perspective in three ways. Firstly, Doka followed Pattison in applying a task-based understanding of coping to both dying and life-threatening illness. Secondly, Doka accepted Pattison's notion of the 'living-dying interval' but expanded the earlier tripartite account of acute, chronic and terminal phases to include two additional phases: a prediagnostic phase, during which an individual might become aware of an indicator of potential life-threatening illness and might contemplate or pursue alternative courses of health promotion in response to that awareness; and a recovery phase, representing events that might occur if it should happen that the illness does not result in death. Again, these additional phases can be noted in my study in the respondents' stories and in my later chapter, *Interpreting the Findings*.

Task theory is vulnerable to criticism insofar as it expresses a cultural bias towards work and achievement. It is possible that it could be subject to criticism in a similar way as are stage-based theories, in that individuals may feel pressurised by caregivers – both formal and informal - to regard their final phase of life as a series of coping tasks. As with any approach, it would be essential to use theory as a guide rather than as a draconian imposition.

Arising from a different standpoint, Rando's (1986) work on anticipatory grief offers some complementary ideas to this discussion of coping with dying. Rando expanded the original concept of anticipatory grief to include not only an individual's reactions to possible impending death, but also to the numerous changes

and transitions which are generally experienced throughout the course of a long illness. This helped her to draw attention to a broad variety of losses, including, at any given point in the dying trajectory, past losses, present or ongoing losses and future losses, that is, the awareness of those which have yet to occur. Rando (1988) concluded that it is misleading to speak of ‘anticipatory’ grief when in fact grief reactions are not limited solely to expectations of future losses. Rando also drew attention to the wide range of reactions and strategies involved in coping with pre-death losses, again emphasising the importance of individuality in behaviour and the need for an individualised response (Corr et al, 1999).

Having begun to explore the territory of living with dying and some of the concepts and theories that have developed from research and practice in this area, I will now move on to explore the particular nature of cancer and its meaning, not only to individuals who are themselves living with a diagnosis of cancer, but also to the wider society.

Dying Revisited- The Special Case of Cancer

For many years, and significantly even in contemporary society, a cancer diagnosis has been seen by many as a ‘death warrant’. Cancer has occupied such an invidious place in the public imagination that the association between cancer and death is now well entrenched in popular myth (McNamara, p 28). Kellehear (1990, p 65) suggested that, if you have a malignant cancer, both “popular and professional views ...define you as dying”.

According to McNamara (2001), it is no wonder that misinformation and fear about cancer takes root in contemporary western societies, as there are a multiplicity of messages about the disease which inevitably create uncertainty. These messages are presented in both professional and lay discourse. We are told of the hope that exists in new cures and therapies and of the drawn-out deaths of those who have ‘lost the battle’ against the ‘dreaded’ disease. “Messages of hope and despair combine, fuelling a cultural terror and exposing our inherent fragility, our fear of death” (McNamara, 2001, p 28)

“No one is more fragile than the cancer sufferer....the cancer sufferer is burdened by the stigma which gives cancer a symbolic life of its own” (Sontag, 1978). “The newly diagnosed cancer patient is debilitated not only by the *symptoms* of the disease, but also by the *symbols* of the disease. Cancer is associated with pollution, with uncontrollable and overwhelming growth, and with evil. ...It is not that we are unsympathetic to the cancer sufferer, it is that cancer has a life beyond the particular disease” (McNamara, 2001, p 29).

Ian Craib (2003), a sociologist who experienced cancer in his own life, soon came to realise “[t]hat as a cancer patient my job was not to draw too much attention to the fact. The world is fragile when someone is dying...we have to tiptoe around the dying and around ourselves” (p 294). Increased life expectancy means that the ‘private’ face of death is something that many of us will not encounter at a personal level until mid-adulthood; those, then, who are dying are consequently in danger of becoming “uniquely isolated, lepers even, because they highlight the Achilles heel of the modern individual” (Walter, 1991, p 306).

Levin (1999, p 30), drawing on the work of Foucault, proposes that part of what drives the many misconceptions and ‘collective terror’ about cancer is that we sense its timeliness: it takes on what Foucault has called an ‘historic individuality’ and has been termed ‘THE illness of our time’ (Herzlich and Pierret, 1987, p55; also Stacey, 1997). Unlike AIDS, which failed to reach the epidemic proportions it was once anticipated to do, everybody knows someone who has been affected by cancer, regardless of age, gender, race or sexuality, and it does not discriminate on grounds of wealth or resources – no-one can see themselves as immune.

Sontag (1978; 1989) has illustrated how cancer in contemporary society is closely associated with death in much the same way as leprosy and tuberculosis were in Victorian England. Despite the increase in survival rates from cancer, it remains frightening because it refuses to be ‘beaten’. Nuland (1993, p 207-210) uses evocative language to describe cancer:

Its cells behave like the members of a barbarian horde run amok – leaderless and undirected, but with a single-minded purpose; to plunder everything in its reach...cancer cells cultivated in the laboratory exhibit an unlimited capacity to grow and generate new tumours...the combination of delayed death and uncontrolled birth are malignancy's greatest violation of the natural order of things. These two factors in combination are the main reasons a cancer, unlike normal tissue, continues to enlarge throughout its lifetime (cited in McNamara, 2001, p 31).

According to Nuland, a physician, cancer presents us with two contradictory messages: one of hope in the survival rates, and another of fear of uncontrollable growth. Messages of hope and fear about cancer are often mixed and people tend to focus on the bad news and fear rather than the positive advances in cancer management.

McNamara (2001, p 31) suggests that one of the reasons why cancer is so feared is the fact that its causation is still not established. Despite numerous clinical studies which have indicated connections between, for example, chronic stress and cancer and between relationship losses and cancer onset (Pearce and Findlay, 1987; Selye, 1986), findings which propose emotional, psychological and social factors to be significant causes of cancer are still highly contentious (Lowenthal, 1989) . As such the mystery remains and cancer continues to be viewed as something which cannot be understood or tamed.

Field (1996, p 256) suggests that cancer is associated with fear and mystery for a number of different reasons, notably, the unexpectedness and untimeliness of its appearance. Although it is not unusual for cancer sufferers to interpret their cancer as a warning to review and change their lifestyles (Dodds, 1997), this understanding is usually constructed in retrospect and it is unlikely that many people expect to get cancer. Likewise, a diagnosis of cancer is often 'untimely', in that it subverts our normal expectations of longevity and as such the threat of death before the 'due' time is all the more difficult to deal with.

McNamara (2001) also contends that cancer is a highly stigmatised disease and this is an added complication for those who are diagnosed. Historically, she writes, cancer has been linked with contagion, and this myth seems to persist to the present day. Sontag (1978, p 43) argues that the ancient Greeks believed the disease could

sometimes be the result of demonic possession or supernatural punishment and, although these myths would not necessarily be openly expressed today, the fears that accompany them still seem to exist in the public mind. The need to address the fear of cancer is the preoccupation of a number of authors: Pinell (1987, p 36) for example, analysed letters written by cancer patients who contributed to a public debate on cancer in France- one patient wrote “Friends avoid you...and it’s a mistake, one should speak about it; it is less frightening”. Balslem (1991, p 161) conducted research within a working-class community in America and discovered a sense of fatalism about the nature of the disease: “As with most minions of fate, cancer may punish those who notice or defy it. To think about cancer, to try to prevent it, is to tempt fate. Cancer testing is ‘looking for trouble’. Respondents seemed hesitant to speak the word ‘cancer’ out loud, and they often referred to cancer as ‘the big C’” (cited in McNamara, 2001, p 33).

For some, the myths around cancer are internalised and there is the sense in which some individuals feel that they have ‘brought the disease upon themselves’. There is evidence that links cancer causation to a range of environmental and lifestyle factors, such as the consumption of alcohol or tobacco, nutritional deficiencies or excesses, reproductive and sexual behaviour, pollution and occupation (New South Wales Cancer Council, 1996), and this kind of evidence can be seen to shift the blame for the disease from some unknown agent to the sufferer. Thus fear of cancer can therefore be further complicated by the guilt individuals may feel when engaging in so-called risky behaviours.

According to McNamara (2001, p 33) “whether we are fatalistic or vigilant in our monitoring of cancer risks, whether we favour reductionist biomedical explanations or psychologically based explanations like the ‘typical’ cancer personality (leShan, 1977; Chen et al, 1995) we still cannot seem to escape the association between cancer and death. They are an unfortunate pair and the myth continues despite advances in cancer control and the hope that exists in the hearts of so many cancer sufferers”. As Pinell (1987) observes, cancer is portrayed as a challenge to rationality – it seems as if cancer is an outcome of a kind of social and bodily disorder which brings about death.

According to McNamara (2001), cancer patients suffer a great weight of responsibility because they are often expected to take up the fight against the dreaded disease and this becomes not just their own personal battle, but part of a far greater narrative.

“Cancer patients stand accused primarily of a failure of will. Small wonder they have been shunned and shamed in our recent history, hidden like a consummate obscenity from public view...[I]n the new age of consumption-driven postmodern enlightenment we are more inclined to rehabilitate cancer patients than punish them, less inclined to isolate and destroy. So today we cajole. We infuse cancer with the power of good thoughts, optimism, and above all will power!” (Levin, 1999, p 106, cited in McNamara, 2001). It seems then that hope and the will to fight are not simply options for cancer sufferers but expectations placed upon them by family, friends, health professionals and indeed the broader society.

Further to this, Lupton (1994) explains that the metaphors of invasion and combat so often applied to cancer are used to convince patients that they must ‘win’ by adopting a positive attitude. “To despair, to lose hope, are frowned on as strategies of dealing with diseases such as cancer” (p 67). Walder (1994, p 67), writing about her own experience of living with breast cancer, explains that she was influenced by suggestions that a positive mental attitude would help her control a recurrence of the disease. However, this represented a greater pressure for her, as she described herself as by nature a ‘worrier’ and was concerned that her own personality would limit her capacity to overcome the disease.

However, some have noted a more positive aspect to the experience of cancer. In her study of individuals living with cancer, Armstrong-Coster found that “Confrontation with a potentially fatal disease can focus the mind; it provides the opportunity for values to be reassessed, priorities to be examined and commitments and relationships to be re-evaluated” (Armstrong-Coster, 2004, p1). Kellehear (1996, p 157) notes that “in the period during and after the crisis, one’s whole way of understanding life may need revision because a major part is found wanting. The meaning and value of one’s life may be called into question.” This questioning

becomes part of a new cancer identity whereby the sufferer tries to make sense not just of his or her illness, but also of life (Mathieson and Stam, 1995, p 284).

Traditional understandings of illnesses like cancer representing a ‘death sentence’ are continually challenged as contemporary healthcare confronts the frontiers of treatment and cure. However, even though death rates of once predictable terminal illnesses are falling, many people are living with the aftermath of the illness itself and/or the treatment regimens. Chronic illness and associated morbidities, together with the ageing of populations in many industrialised countries, have the potential to change the community’s demands on healthcare systems.

How, then, should we respond to the changing nature of cancer in Western society, and what models are available to us to help us develop practice with people who are living with this disease?

The Role and Responsibility of Social Work to People Living with Cancer

According to Small (2001, p 961) “there are close links between the philosophy and practice of palliative care and that of social work” and social work has a particular contribution to make to the care of people who are living with life-threatening illness in three main respects: that social work has always been concerned with responding to loss; that social work brings a ‘whole system’ approach, putting individual experience into a wider context and social work is concerned with helping people to ameliorate the practical impact of change. What characterises social work in the context of life-threatening illness is its ability to recognise the holistic needs of individuals and families, and how, despite recent trends towards care management in mainstream social work (Lloyd, 1997; Lloyd, 2000), palliative care social work as practised in hospices and other specialist settings has by and large managed to retain its traditional casework approach, so valued by service users, as evidenced in a recent national study by Beresford et al (2007).

In my experience as a social worker in a hospice from 1995 to 2004, the role of the social worker complemented that of the multi-disciplinary team by ensuring that a

psychosocial model of care was offered to patients and families alongside the medical model, and that service users were encouraged to identify and achieve self-defined goals, to fulfil their potential and to live their lives for as long as was possible – essentially an individualised approach to care was provided which counteracted some of the more restrictive aspects of the medical interventions which service users would often have to undergo.

Intrinsic to this approach is a recognition of the spiritual needs of service users who require palliative care services: according to Everard (2005, p 129) “In focusing on the needs and wishes of their clients, in using their skills and experience to facilitate the expression of spiritual and emotional pain, and in being willing to enter at some level into the search for meaning in, and some resolution of, the suffering that patients and their families experience, social workers in palliative care settings make an important contribution to the meeting of the spiritual needs of their clients.”

However, Clausen et al (2005, p 283) found that, although many patients and carers had clearly expressed psychosocial needs, which could clearly be met by social workers, few, if any, had any social work involvement. This was partly attributed to a lack of understanding on the part of the wider team about the roles and tasks of social work, and a reluctance on the part of potential service users to request a social work assessment, fearing the social stigma associated with this. Nevertheless, Beresford et al’s (2007) research determined that what palliative care service users who did receive social work intervention desired from and valued about the service they received was the ability and willingness of the worker to ‘journey’ with the, providing continuity of care and acting as a guide into the unknown (Beresford et al, 2007; also Miller, 1990; Clausen, 2005; Reith and Payne, 2009).

The challenge to social work today would seem to be for agencies, organisations and individual practitioners to recognise the changing world of cancer care and to enable social workers to reach out to those who are living with, as well as dying from, cancer, recognising that the need for psychosocial intervention and support is ongoing and that the same skills that are valued by those who are dying may be equally as applicable to those who are surviving.

Narrating Cancer - Storytelling as a Means to Understand Experience

“Over the last few decades, facing death from cancer and other illnesses has become a focus of interest, with personal stories of the experience now occupying a prominent place within contemporary culture. This is particularly evident in literature, magazines, on the Internet, in newspapers, books and television, film and radio drama” (Bingley et al, 2006).

“From the 1950s, when relatively little was written about facing death from a personal perspective, there has been a steady rise in the number of published narratives describing the personal experience of life-threatening illness. In the last decade, with the creation of the Internet, there has been an exponential increase in unpublished, web-based writings (Pitts, 2004). More people seem to want to share their stories of the process involved in facing, and wherever possible, ‘fighting’ or ‘coming to terms with’ their illness. During the past half century, English narratives written by those facing death from cancer and other diseases reflect a major sociological and perceptual shift, in particular towards higher expectations of medical provision as treatments and survival rates improve and end-of-life care services develop. Narratives specifically about dying from cancer are a recent phenomenon, only starting to emerge as a distinct genre in the 1970s. It would seem that a resurgence in academic interest has also been prompted by the volume of ‘illness narratives’ in the public domain” (Bingley et al, 2006).

I contend that these narratives provide a rich source of evidence of the experience of living with cancer, from which we can begin to deduce a more coherent theoretical framework to aid our understanding of what the experience of cancer might mean for individuals.

This method of developing understanding in respect to the experience of living with dying is not new. According to Dame Cicely Saunders, “We have helped people to listen to dying people and to hear what they’re saying, and the challenge for the future is to keep on listening” (interview, cited in Walter, 1993 p 67). For Saunders, it was important to give people who were living with life-threatening illness the opportunity to tell their stories, in order to increase public awareness of issues of

death and dying, to improve public understanding and reduce fear and ultimately to improve the care and support that people in this situation receive.

Kubler-Ross in America in the 1970s also told people's stories and these stories also had an emotional effect on people. As a result, things did change – the impersonal nature of hospital care was exposed by the very personal stories of the patients who suffered within them. If the premise of contemporary health and social care is that the patient (or service user) should come first, then it is vital to let the person (him or herself) speak, not only as has often been the case through the mouthpieces of professionals and academics such as Dame Cicely and Kubler-Ross, but also through the many printed case studies, biographies and autobiographies (Walter, 1994).

For health and social care professionals to truly understand an illness from inside an individual's experience necessarily requires taking a longitudinal view of issues like when the illness began, how the person understands their illness, how it affects them, what adaptations they have made, in other words, listening to their stories. The individual meanings given to living with a chronic illness are shaped in part by relationships with other people and the expectations shared in those relationships (Kleinmann, 1988). While each person's story will be highly individual, Frank (1995) suggests that the activity of telling the story is in itself empowering and can contribute to collective knowledge as it provides an opportunity for healing, creates empathetic bonds between the teller and the listener and thus widens the 'circle of shared experience' (p xii). The gathering of these stories of individual experience, as opposed to seeking one common and dominant cultural experience, may assist others in understanding the 'illness journey'.

Stacey, however, warns against an unquestioning acceptance of the veracity of these narratives: "Death confers authority upon the narrative and the narrator...Such an authority is conferred on cancer narratives by virtue of their subjects. Death has been reckoned with and the stories that emerge bear the weightiness of a promised enlightenment...Narrative authored by 'cancer survivors' offers readers a mode of witnessing the person's uniqueness and special qualities; in nearing death these brave individuals have revealed their best qualities to the world" (Stacey, 1997, p

243-244). Stacey elaborates, citing Bronfen (1992, p 80, in Stacey, 1997, p 244): “All s/he has to tell is imbued with authority and it is the ‘authority’, arising from the aporia of speaking or writing in the shadow of death and against it, that lies at the origin of all [such] narratives. Death is the sanction for all that a storyteller might relate. She or he borrows authority from death.”

But individual stories may also add to the postmodern view of illness and death and frightening and uncontrollable, often by the very fact of emphasising the highly personal nature of individual experience (Seale 1998). Kellehear and Howarth (2001) acknowledge the place of isolation and uncertainty as part the experience of cancer – the cancer journey is an ‘unscheduled journey’ (p 71). The tension of upholding both the individual and the collective experience is one that Kellehear (2007) suggests is like ‘gazing into a reflecting pool’ – that beneath the individual images of self, lie the common influences of history and culture, which contribute towards the shaping of identity.

Exploring the Experience of Living with Cancer – Three Conceptual Frameworks

Through my reading of the stories of the experience of individuals who are living with cancer and my review of the research studies on living with life-threatening illness, and specifically cancer, I have discerned three major concepts which have served to enhance my theoretical understanding of the experience. These are, as follows, biographical disruption, liminality and survivorship.

Biographical disruption and cancer

The concept of biographical disruption was introduced into the discourse of chronic illness by Bury in 1982 as a means both to describe people’s experiences of chronic illness and as a framework to understand how people respond and adapt to such illness (Hubbard et al, 2010; Lawton, 2003) More recently, however, researchers in the field of cancer have sought to explore the potential of this concept for

understanding the experience of living with cancer. Cancer has traditionally been conceptualised as an acute illness, but with the advances in earlier diagnosis and improved treatment of cancer, more people are living longer with the consequences of cancer, and thus it is a disease which may be seen increasingly to fall within the category of a chronic condition. Significantly, Tritter and Calnan (2002) argue that although there are common features in the experience of cancer and chronic illness, the differences are all too significant and cancer should not be defined as a chronic condition. However, the core condition for biographical disruption, as defined by Bury in 1982, is that it is precipitated by a disruptive event, a major disruptive experience or a critical situation. In cancer, the onset of illness can be seen to 'disrupt' people's assumptions about their bodies, themselves and the social world in which they live, and bring to the fore thoughts of pain, suffering and death, which are normally only considered to be distant or remote possibilities in life which can be ignored or are perceived as things that happen to other people. Thus, according to Cayless et al (2009), while biographical disruption has not usually been applied to acute illness, it can be seen to be a useful concept for describing and explaining people's experiences of cancer, particularly within the first year.

Furthermore, I would argue that biographical disruption is a relevant concept for describing and explaining the experience of cancer for some individuals because a diagnosis of cancer represents a threat to identity. Whilst it must be acknowledged that 'battle' metaphors for cancer are contested, the term 'threat' here is used here specifically in relation to the context of biographical disruption. Thus I would argue that the application of the concept of biographical disruption to cancer is appropriate.

Like Bury, Charmaz (1994) suggests that chronic illness raises people's awareness of death and disrupts their perception of themselves, particularly if the individual considers him or herself too young to die, or defines themselves as healthy and has no personal experience of illness within which to contextualise the experience. This concept of disruption, which can be seen as an assault on the 'self', has been applied directly to the experience of cancer, for example, in studies by Exley and Letherby (2001) and Shaha and Cox (2003). Disruption of a person's biography can affect not only how people view themselves but also how they think they are viewed by other

people. It can lead to social isolation and a sense of ‘difference’ from contemporaries (Cayless et al, 2009). This again is a characteristic of the experience of living with cancer, as will become evident in the stories of my respondents.

Bury’s concept of coping is also relevant here, as it refers to cognitive processes whereby individuals learn to manage their illness and “involves maintaining a sense of value and meaning in life, in spite of symptoms and their effects” (Bury, 1991, p461). Examples of coping include normalisation and ‘bracketing off’ the impact of the illness so that the effects on identity are minimised. According to Bury (2001) there are two processes of normalisation. People may normalise in the sense of trying to keep their pre-illness lifestyle and identity intact by either maintaining as many pre-illness activities as possible and/or by disguising and minimising symptoms. Other people find ways to incorporate their illness into an altered lifestyle so that ‘normal’ life is reorientated around the illness, thus ‘containing’ it. Again, both these orientations are evident in the lives of my respondents, to follow.

Identity and Loss of Self

It is the concept of identity and loss of self within the context of illness which has formed the focus of Charmaz’s work (Charmaz 1983; 1994; 1995 and 2002). According to Hubbard et al (2010) identity requires empirical validation in everyday life, yet, with the onset of chronic illness, the daily life upon which former identities have been built will also have changed.

According to Charmaz (1983), loss of self is experienced by people with chronic illness because their former actions, lives and selves are now threatened by illness. She notes that whereas acute illness may cause only temporary disruptions of self, chronic conditions can lead to continued losses of self.

Charmaz (1995) examines how people repair loss of self, brought about by chronic illness. Some people ‘struggle against illness’ and engineer their lives in order to regain, restore and preserve a pre-illness sense of self and identity. Her analysis of men’s experience of illness (Charmaz, 1994) for instance, illuminates some of the

processes employed to preserve pre-illness identities. 'Bracketing' is a means of removing illness from the general flow of life and confining it to a separate place. Viewing illness as an enemy serves to objectify and externalise it, which is another process that she found men in her study were using to preserve a pre-illness identity. Others, however, adapted to the illness and established a new identity in the process. 'Adapting implies that the individual acknowledges impairment and alters life and self in socially and personally acceptable ways' (Charmaz, 1995, p 657). The extent to which adaptation is possible and successful is dependent on context. She suggests that the middle-class, professional men in her study are fairly well able to alter their paid work to fit around their bodily needs. Hence, they are able to maintain an identity, which in this example is paid employment, by altering their daily activities to accommodate the impact of illness (see Hubbard et al, 2010; Lawton, 2003)

The Significance of Context in Biographical Conceptualisation

Further research that has used the concept of biography and identity to understand health and illness has highlighted the fact that the onset of illness may not necessarily be experienced as disruptive. In particular, Williams (2000) and Faircloth et al (2004) infer that those who experience multiple chronic co-morbid conditions may not experience the onset of another illness as biographically disruptive but rather as one 'event' in an ongoing flow of events. This experience has been termed 'biographical flow' (Faircloth et al, 2004). In a similar vein, the concept of biographical disruption may not be applicable to those who have encountered adversity and material deprivation throughout their lives or who anticipate ill health because of their life circumstances, perceived life expectancy and age. For these individuals, the onset of chronic illness may be just another facet of a 'hard life' (Hubbard et al, 2010) which may even be biographically anticipated. This may not amount, therefore, to a profound and fundamental disruption of biography, but rather to the continuity of 'normality' (Faircloth et al, 2004; Hopkins, 2004; Levealahti et al, 2007; Pound et al 1998; Richardson et al, 2006). Thus, these challenges and qualifications suggest that universal prescriptions of chronic illness as biographical disruption cannot be justified.

Bury's work (1982, 1991) focuses on how people accommodate and seek often to normalise the disruption illness may cause in their lives. He suggests that individuals adopt methods of legitimising their illness and explaining its impact on the self with reference to their life and biography. Bury (2001) describes three different, but linked concepts, which illuminate this process (also Cayless, 2009): 'coping', which refers to the methods the ill person uses to manage his or her situation emotionally; 'strategy' which refers to the way in which the individual tries, through his or her actions, to deal with illness; and 'style', which reflects the notion that different people have different attitudes towards illness.

Other researchers have explored the disruption to and renegotiation of identity through the experience of cancer (Exley and Letherby, 2001; Mathieson and Stam, 1995). In terms of sexuality and sexual function for men with prostate cancer, for example, elements of everyday life which were previously taken for granted are threatened by serious, often unpredictable and potentially long-lasting symptoms, treatment and side effects (Cayless, 2009).

The analysis of the literature of biographical disruption and flow and the threat of illness to identity aids our understanding of possible issues for those who are living with cancer and provides a potential framework for intervention in this still somewhat uncharted new territory. Biographically informed approaches to care complement a narrow medical focus on the body and physical symptoms and present the opportunity to broaden our understanding of illness to include social and spiritual dimensions, and as such to support individuals to manage the psychosocial consequences of their diagnosis.

Liminality

Kleinmann (1988) has documented the 'apartness' of people who are seriously ill with particular clarity in his work on illness narratives. This state of 'apartness' has also been termed 'liminality' and can be seen as a territory which the survivor of serious illness enters and which persists in some form or other for the rest of the patient's life. It resembles the state referred to in Frank (1995, pp 8-13) as

membership of the ‘remission society’. It is a concept which derives from social anthropology and was used by van Gennep in 1909 (Van Gennep, 1960) in his study of rites of passage. For van Gennep, rituals marked a process of ‘passing through’ a phase of social evolution. During a period of separation from the rest of society, the person was prepared by purification. This phase of separation was followed by a phase of transition, when the initiate had left their former state, but had not yet entered the new one. This stage was termed by van Gennep as *liminaire*, meaning ‘of the threshold’ (Little et al, 1998).

Turner (1979) elaborates on the meaning of the term, referring to it as a state of being ‘betwixt and between the normal, day to day, cultural and social states’ (Turner, 1979, p 94), a particular space in which normal societal roles and status may be relinquished or taken away.

In the context of illness, Frankenberg (1986) follows Turner in using the term to describe periods of disruption in life caused by illness, in which structure and routine are abandoned. Murphy et al (1988) used the term to describe the social view of people with chronic disability as in a state which was “cloudy and indeterminate” (p 238). For Little et al (1998), however, liminality is not seen as a phase to be passed through, but rather as an “enduring and variable state” and as such, “the labelling inherent in the cancer diagnosis is sufficient to induce and maintain liminality” (Little et al, p 1490). Within the context that Little et al apply to liminality in relation to cancer, and based on their research with adults living with colorectal cancer, it can be experienced in two stages – the immediate phase of acute liminality (upon diagnosis) and an enduring phase of sustained liminality, which may last for the rest of the individual’s life.

In existentialist thinking, the concept of death and mortality is ever-present in life, and thus it is possible to argue that liminality is the mode of life in which every person lives, regardless of their relative health and well-being. The certainty of death, according to Heidegger, is the fundamental confirmation of our existence in the world. In former times, illness was part of the irregular, unpredicable trajectory of everyday life, an expected episode in ‘normal’ life, as were fighting wars and engaging in physical labour. However, in modern times, an awareness of

death is no longer considered to be part of 'normal' life and, according to Little et al (1998, p 1491), "most of us do not carry this dread in the forefront of our minds, nor do we live each day with the fear of dying". However, for someone with cancer, the inevitable confrontation with mortality may bring thoughts and fears of dying to the fore in everyday life, and this can be considered part of the experience of liminality, with each hospital visit being a reminder of the threat to life.

Becoming 'other'

Along with the personal feeling of 'apartness', according to Little et al (1998), society may impose a particular role on the sufferer within this liminal state, which may conflict with the way in which that person would otherwise choose to act. They give the example of two contrasting autobiographical narratives of death, written by Ingelfinger (1980) and Broyard (1992) respectively. Ingelfinger was a physician who died of stomach cancer and whose colleagues expected him to retain the professional identity of a clinician to whom they would defer to the end of his life. His requests for advice and support went unnoticed and he remained frustrated and disappointed by his colleagues' 'respectful' treatment of him. Broyard, however, similarly a physician, with prostate cancer, was able to recognise what was happening and how he was perceived by others in the medical profession, and was able to 'reconstruct' his experience and to anticipate the behaviour of others towards him. According to Little et al (1998, p 1491) "This difficult process of looking backward to make sense of a life under the shadow of its boundedness and of confronting the entropy of the future is made more complex by the restriction of approved roles. There is little wonder that the experience of liminality is so unsettling..." (see also McNamara, 2001, p 35 and Froggatt, 1997, p125)

An episode of serious illness removes the ill person from their 'normal' life experience and passes responsibility for their continued existence and for the shape of their life trajectory to another agency. The difficulty of experiencing liminality through life-threatening illness in today's society is that it is not understood, society does not have the natural mechanisms of religion and ritual, of rites of passage, to encompass and support the individual and this can increase the sense of loneliness on the part of the person in the liminal state as they are now often referred to the

services of professional counsellors, psychologists and therapists, which are “supplied by the very system which creates and maintains the sense of alienation”. (Little et al, 1998, p1491).

“The telling and hearing of news of serious illness suspends meaning, challenges beliefs and confronts us with the boundedness of our time and space. “ (Little et al, 1998, p 1492). In the particular case of cancer, Kleinmann writes: “Cancer is an unsettling reminder of the obdurate grain of unpredictability and uncertainty and injustice - value questions, all – in the human condition. Cancer forces us to confront our lack of control over our own or others’ death. Cancer points up our failure to explain and master much in our world.” (Kleinmann, 1988, p 20)

The moment one suspects that something is wrong is when enters the liminality of cancer. With the diagnosis of a potentially fatal illness one is ‘set apart’ from others who do not have the same concentration of mind on their own mortality. As mentioned earlier, Little et al (1998) distinguish between two stages of liminality. The initial acute phase begins when an individual’s suspicions that something is wrong are confirmed, when he or she hears the ‘bad’ news and experiences the existential threat. “Acute liminality represents a discontinuity of subjective time, in which powerful forces operate to change perceptions of time, space and personal values” (Little et al, 2006, p 1492, also Rasmussen and Elverdam, 2007).

Sustained liminality follows the acute phase at an indeterminate time, depending on a variety of physical, social and psychosocial factors, including how the individual managed the acute phase, the availability and acceptance of external support, to what extent the diagnosis represented a disruption to the biography of the individual, and the impact and outcome of the treatment. Little et al (2006) found that patients in this phase began to regain control over some aspects of their lives whilst remaining aware of their ‘differentness’ from others, the difficulty of communicating the nature of their experience and a sense of ‘boundedness’ in time, space, work, power and social functioning (p 1493). Frank (1995) confirms this state of sustained liminality from his own experience. It would seem that some aspects of sustained liminality can last for the rest of the life of someone who has survived cancer. Successive medical appointments prolong the experience, as individuals are

expected to assist the clinician in charting their own illness trajectory, identifying signs and symptoms, always in the knowledge that the news may not be good, and thus reinforcing the state of 'cancer patientness' (Frank, 1995, p 1493, McNamara, 2001).

People who have had cancer remain identified as people who have (had) cancer, regardless of whether they accept this identification: "...they enter, along with sufferers from chronic illness and those who have survived serious threats to life, a phase of sustained liminality, in which adaptive mechanisms are repeatedly formulated and reformulated" (Little et al, 2006, p 1493; see also Tischelman and Sachs, 1992). "Cancer changes the sufferer's life forever, for even if that person is able to go on living, he or she lives under threat of possible recurrence of the disease" (McNamara, 2001, p 33-34).

According to Cayless (2009), the notion of liminality attempts to explain the "chaotic and often ambiguous state where men (sic) have few cultural scripts to draw upon to classify and manage their illness". Indeed, the promotion of the concept of patient choice can exacerbate the feeling of uncertainty: according to Navon and Morag (2004) in their study of men with prostate cancer, the very nature of the disease with its range of treatment choices, and the possibility of deferring the start of treatment, leaves many men trapped in a 'neither/nor' state of limbo or liminality.

Forss et al (2004) have interestingly applied the concept of liminality to women who receive news of an abnormal cervical smear test result, which can be seen as the very epitome of an experience of being 'betwixt and between' the worlds of health and illness.

An exploration of liminality is useful to this study because it provides another category of understanding of the dynamic processes of accommodation and adaptation that a person living with cancer may experience during the course of their illness. In common with biographical disruption and survivorship (below), liminality is a concept which has at its core the significance of individual experience, while at

the same time offering a broad and flexible interpretive framework within which to understand that experience (Little et al, 2006; Cayless et al, 2009).

Survivorship

The term survivorship first appeared in the medical literature in the 1960s with reference to life after myocardial infarction (Lew, 1967). By the 1980s the concept of survivorship had begun to appear in cancer-related literature, incorporating not only the notion of *biomedical* survival but also the *psychosocial* perspective, although it was mainly limited to the experience of paediatric survivors reaching adulthood (Jaffe, 1975, in Doyle, 2008). Following the publication of the article *Seasons of Survival* (Mullan, 1985), the idea of how the experience of cancer survival might evolve over time came to be considered and, as described earlier in this chapter, the growing literature of autobiographical work describing the individual experience of surviving cancer provided a rich source of evidence of the experience (Bingley et al, 2006). Nevertheless, according to Doyle (2008) there has been little progress in the conceptualisation of cancer survivorship, despite the significant rise in the number of cancer survivors, and the term continues to be used interchangeably with related terms, such as ‘people living with/ through cancer’ . Indeed this latter nomenclature is that chosen by the Scottish government in policy on cancer ‘survivorship’.

According to O’Connor (2008, p 106) “Traditional understandings of illnesses like cancer being a ‘death’ sentence are continually challenged as contemporary healthcare confronts new frontiers of treatment and cure...If we acknowledge that the illness experience includes a longer period of living with illness and its effects, a longitudinal understanding of illness that incorporates the whole illness ‘journey’ is appropriate.” Thus it would seem that a consideration of the concept of cancer ‘survivorship’ is required.

Due to developments in public health policy in terms of screening and early detection, together with more effective treatments, increasing numbers of people in industrialised countries with once terminal illnesses like cancer consider themselves

(or are considered to be) ‘survivors’. However, seeking a definition of ‘survivor’ is difficult, since there is subjectivity to this status as well as a changing professional understanding, depending on different phases of illness and treatment.

Although the concept of cancer survivorship appears increasingly in literature relating to the experience of cancer and in health and social care policy on the care of people living with cancer, it still does not appear to have a precise definition. It appears, therefore, to be “an emerging but immature concept as yet unsupported by any theoretical framework” (Doyle, 2008, p 499).

There is a lack of consensus in the literature as to when someone becomes a cancer survivor. For some authors, it is a process which begins at diagnosis (Breaden, 1997) but others suggest that a person must live five years before being regarded as a survivor (Carter, 1993). If defined biomedically, survivorship may mean the period after therapy ends: however, some support groups take the view that it does not matter if there is recurrent or persistent disease, and anyone living after a diagnosis is a survivor (Little et al 2000; also see Liminality section, above).

The work of Little et al (2001) recognises the ambivalent nature of the concept of survivorship, contrasting “the inspirational literature about individual resilience with that of the difficulty of ‘being’ a survivor” (O’Connor, 2008, p 115), which status can be characterised by feelings of vulnerability to the ever-present possibility of recurrence and by the possible subsequent impact of this on all aspects of life. Shanfield (1980) concluded that the cancer experience was a permanent one, characterised by vivid memories of the illness and recovery period, coupled with an enduring sense of one’s own mortality and vulnerability (Doyle, 2008,).

Little et al (2000) connect the concepts of liminality and survivorship by describing the potentially life-changing nature of the cancer experience, in that “cancer survivors pass through the space of illness but do not return to their world as it was before the illness” (Doyle, 2008, p 503). Payne suggests that survivors “have to simultaneously inhabit the world of the ‘healthy’ population and the world of the patient” (Payne, 2007, p 430), which suggests a sense of having to exist within two communities and the need somehow to be able to cross the divide, as in the state of

liminality, described above. The extent to which individuals are able to ‘bridge’ this gap or how far the feelings of ‘otherness’ dominate will affect how far they feel integrated or isolated as a cancer survivor.

Little (2001) suggests that, in developing a discourse of survivorship, several important factors need to be taken into consideration, namely,

- a) that identity is constructed and fluid, and may involve the presentation of multiple ‘selves’ in relationship to others
- b) surviving an illness such as cancer may evoke feelings in the ‘survivor’ of vulnerability, disempowerment, the need to preserve ‘face’ and the pressure to behave as though things were ‘back to normal’, the need for approval and the pressure of ‘survivor guilt’
- c) the nature of the ‘extreme’ experience of having (had?) cancer and the effect this can have on one’s perception of oneself

Continuity of memory is a distinctive part of identity which, among other things, serves to construct the individual’s narrative of illness in survivorship (Little et al, 2002; see also discussion on identity and biographical disruption, above). One aspect that is important in understanding cancer survival is described by Little as ‘future memory’ (p 171) which involves the individual imagining looking back at stages of life that are yet to occur, for example, a young man imagining himself as a grandfather and trying to comprehend what he anticipates that experience to mean. “The discontinuities in narratives reflect discontinuity in identity, especially if these anticipated life experiences are important aspects of the individual’s identity” (O’Connor, 2008, p116).

Acceptance of the survivor identity may take considerable time, and may actually be resisted by or be impossible for some people. Partly this is due to different meanings that people may attach to the term, both within and without the ‘survivorship community’. For example, if there is an underlying expectation that survival means that the person’s life will return to ‘normal’, by which I mean that previous roles and relationships will be resumed, work will recommence and patterns of life restored, then this may be neither possible nor desirable on the part of the ‘survivor’, however much it may be desired or expected by those around him or her. The few studies that

have been conducted into the return to work after cancer have shown that it can be highly problematic, involving readjustment or acceptance of a change in role, expectations of self and the issue of disclosure (Rasmussen and Elverdam, 2008; Tehan, 2006) and can be related to cancer survivors' changed perception of time and reassessment of the work-life balance (Rasmussen and Elverdam, 2006).

Doyle (2008) found that the experience of cancer survivorship was often characterised by the concept of uncertainty. This has been attributed to the fear of the possibility of recurrence (Leigh et al, 1995), long-term uncertainty about genetic links (Vachon, 2001), feelings of powerlessness on completing the treatment (Carr, 2004; Breaden, 1997) and the anxiety of 'losing contact' with the treatment team (Diamond, 1998), which Mullan (1985) graphically describes (on the part of the professionals) as "leav[ing] them [the survivors] on the dock to cough and splutter on their own in the belief we have performed all we can" (1985, p273, cited in Doyle, 2008, p506)

Doyle also discovered the potentially transformative power of the experience of surviving cancer, both for the better or for the worse. "The opportunity to redefine oneself does not occur often in life, but a cancer diagnosis may be one of those occasions" (Doyle, 2008, p 504). This redefinition could be seen as positive, with accounts of individuals either developing a deep sense of purpose in life or a need to leave a legacy (Rendle, 1997; Armstrong, 2001), or negative, accompanied by the fear of change, or issues around body image after surgery preventing people from developing intimate relationships or being unable to leave unsatisfactory ones (Auchincloss, 1995).

While there were those who did not characterise their experience as life-changing - for example, Killoran et al (2002) in their study of long term cancer survivors, found that nearly all the participants described the experience as 'largely unremarkable' (p 209, cited in Doyle, 2008, p503) - the overwhelming evidence from the literature is that cancer is an experience that in some way disrupts people's lives and identity. "Life after cancer can be so different from how it was before, and it appears that there is no right way to find the 'new normal' and no researched model that people can follow" (Doyle, 2008, p 504). This would seem to provide a link to the literature

above on the possibility of a cancer diagnosis to evoke biographical disruption rather than continuity and the need for the health and social care team to try to help people to find their way through this ‘unchartered territory’.

Overwhelmingly, the experience of cancer survivorship seems to ‘mark out’ those who have experienced it as different from those who have not. Little et al (2000) describe three universal elements common to cancer survivors, namely, the adhesiveness of the label ‘cancer patient’, an awareness of the body’s fallibility, coupled with a heightened awareness of one’s own mortality, and lastly the knowledge that one has lived through an intense and unique experience (Doyle, 2008).

The concept of ‘death salience’ is relevant here, described by Little and Sayers (2003) as “the reflective awareness in a survivor that a mortal extreme experience could have led the subject down a fork in the road of serious illness to death and personal extinction” (cited in Little et al, 2004), which implicitly contains a concomitant awareness that there might be a ‘next time’ and that the outcome next time might be different.

A number of authors refer to the discourse of fear that may accompany cancer survivorship, which could be related to the concept of death salience described above. However, Craib (2003), when he experienced fear in the face of his own diagnosis of cancer, surveyed the sociological literature on death and dying and “found practically nothing which speaks to this fear”. Kaiser (2008), in her study into the experiences of people living with breast cancer, expresses the concern that it is important to recognise that survivorship is a complex experience, not simply categorised by the feeling that one is ‘lucky to be alive’ (Breaden, 1997), and that “in constructing a positive...definition of survivorship, the breast cancer culture has left many women searching for representations which acknowledge their fears and the continued presence of cancer in their lives” (ibid, p 86).

Similarly Rosedale (2009) discovered that in the years beyond diagnosis and acute treatment, the physical, emotional and social effects of breast cancer may create on-going crises and challenges that trigger the acute experience of loneliness. “Survivor

loneliness was characterised by a paradox: women strove to accept their personal sense of loneliness and live more authentic, connected and vital lives even as they withheld truths and participated in inauthentic acts to protect others, for example, withholding aspects of one's experience to protect others who had not been through the experience of cancer" (p 176).

It is, of course, important to recognise both the things that cancer survivors have in common while at the same time recognising the uniqueness of the experience, and particularly to acknowledge that there may be differences across cancer types, for example, a number of authors relate the particular experience for women of surviving breast cancer (Broom, 2001; Wilkinson, 2001). It is important also to allow for difference in social and cultural background and to acknowledge how this may affect 'survival behaviour', for example, in her comparative study of the coping styles of Anglo-American and Japanese –American patients, Kagawa-Singer found that Japanese- American patients seem to 'deny' the fact that they are living with cancer, as this seemed to ensure a harmonious balance in relationships with family and friends, whereas Anglo-Americans were much more open about their experiences and this ensured for them sympathy and support (Kagawa-Singer, 1993).

As Rosedale (2009) concludes, in respect of breast cancer "As even more women live with the on-going symptoms and an awareness of their mortality, treatment should focus more on survivorship. Women's experiences and descriptions of loneliness point out that breast cancer is 'far from over' in their lives" (p.184).

In the interviews I conducted with people living with cancer, and which will be analysed in the forthcoming chapters, I observed for myself how far their experience 'fits' the conceptual frameworks described above, as individuals navigated their own paths through the system, and how this can influence future practice as we seek to develop services which respond to the changing nature of cancer in contemporary society.

PART TWO

ANALYSIS AND

FINDINGS

Methodology

Introduction

My research topic derives from my nine years of practice as a Social Worker in a community hospice, during which I encountered a great variety of individual reactions to the diagnosis of a life threatening illness, and had the opportunity to observe at first hand the different ways in which individuals approached this phase of their lives. As a member of a multi-disciplinary team I was able to explore social and medical approaches to care, and how these could affect the way in which individuals were supported in managing the psycho-social transitions necessitated by their illness and the possible threat these posed to their identity.

My work on the two case studies which I have submitted towards the professional doctorate has likewise served to enhance my understanding of these issues. In each study, the individuals examined approached the diagnosis of cancer in very different ways as a result of their life experience, attachment styles and coping mechanisms developed over time (Taplin, 2005). According to McNamara (2001, viii), “dying is a chaotic and uncertain process”; however, in my experience, the lives of people with a life-threatening illness are seldom altered “in radical ways which contradict the usual social positions and expectations they have had” (Kellehear, 1994, cited in McNamara, 2001, p 67). What interested me particularly through my exploration of the behaviour of these two women in the face of this potentially devastating experience was the individuality of their experiences, the contrast between their approaches to their illness and the discovery, reinforced by my practice as a palliative care social worker, that living with life-threatening illness could have both positive and negative dimensions.

Katherine Shonfield, who herself had been diagnosed with cancer, made the following powerful statement, which seems to encapsulate the inspiration for my research topic: “‘Peter Pan felt a drum beating within him and it was saying, to die would be an awfully big adventure.’ However, doctors give you only two alternatives, to be miserable and give up, or to be cheerful and fight. But just as there are many ways of living, so there must be many ways of being ill. Amongst all the options open to me, cancer could be my big adventure” (Katherine Shonfield, Hospice service user, cited in Rosetta Life Press Release 29 April 2002). Fascinated by this approach, and drawing on my professional and research experience, I have defined the focus of my research as follows:

‘To explore individual experiences of and reflections on living with cancer’

I have chosen this subject not only because it has the potential to subvert the common perception of being diagnosed with cancer as something entirely negative, but also because I would agree with McNamara (2001, p 54), who claims that, apart from a few notable exceptions (for example, Kellehear, 1990; Nuland, 1993) “Much of the literature about death and dying avoids the [potentially] painful and personal approach of discussing the actual experience of dying”. While I am very much aware of the sensitivity of this topic and the importance of conducting the research according to clear ethical guidelines, which protect both potential respondents and the researcher herself (Lee, 1993, p 6; see also later, under Ethical Issues) I nevertheless believe that research in this relatively unexplored area could “lead to substantial good in terms of increasing knowledge” (MacIntyre, 1982, cited in Lee, 1993, p 21) not only of professionals within the hospice movement, but also of current and potential patients and carers and the wider community for whom a diagnosis of cancer remains one of the greatest fears, forcing us as it does to confront the reality of our own mortality.

The aim of this enquiry is to contribute towards the body of professional and public knowledge about this group of service users and to inform policy and practice in this sensitive area. This chapter examines how I developed my research question and determined my choice of methodology, research design and methods. The chapter will also explore how the research sample was obtained and outline the ethical considerations inherent in the design, conduct and sampling.

A careful consideration of ethical issues has played a crucial and challenging part in this study which seeks to gain an understanding of, and to draw lessons from, the very personal experiences of the men and women who have entrusted their stories to me. It is my responsibility to ensure that that privilege is treated with respect and that their stories are told honestly, accurately and purposefully. The chapter will conclude with a reflexive account of what has been learnt from the process, in terms of what worked well, what could have been done differently, the impact of the researcher on the research and the impact of the research on the researcher.

The Development of Research in End-of-Life Care

Research in end-of-life care can be traced back to the origins of the modern hospice movement, which in Britain is mainly derived from the work of the late Dame Cicely Saunders in founding St Christopher's Hospice in Sydenham in the 1960s (Clark and Seymour, 1999). Early research, in line with Saunders' philosophy of holistic care and the emphasis on considering mind, body and spirit in the 'total' care of patients (Saunders, 2002), involved not only clinical studies to evaluate the effectiveness of new methods of pain and symptom control, but also narrative studies which involved talking to patients about their experiences of dying. However, this promising research impetus does not seem to have been maintained, and it has been acknowledged that, despite the proliferation of hospice and palliative care services,

and major developments in the management and care of dying patients, “rigorous evaluation of these developments or well-designed intervention studies have been most noticeable by their absence” (Field et al, 2001, p 3). Likewise, the focus of research seems to have narrowed to exclude psychosocial care - in an article published in the journal *Palliative Medicine* in 1996, Corner undertook a selective overview of palliative care research published between 1966 and 1982, and discovered that the majority of studies focussed on pain and symptom control. She concluded: “Research in palliative care appears to date to have concentrated on evaluating the services it provides, on quantifying the symptoms patients experience and to a lesser extent on the experience of patients themselves” (Corner, 1996, p 207, cited in Taplin, 2006).

However, as rates of cancer survival increase and the medical and social management of cancer generally improves, the evidence and research base is also consolidating. During the 1990s the demand for research in healthcare in the UK was strengthened by reforms in the Health Service and driven by National Standards focussing on cost effectiveness and evidence-based delivery of care. This has included palliative care, even in the voluntary sector, which is seen as an integral part of the wider framework of healthcare commissioning. However, Higginson (1999) has noted that palliative care is notoriously difficult to measure in terms of its effectiveness, particularly in regard to the quality of life of patients with progressive illness. This continues to be reflected in the research studies undertaken, for example, Jubb (2002, p 344) cites a study by Johnston et al in 1995, in which it is claimed that “Studies evaluating the experiences of the dying account for only one per cent of the total body of literature on palliative care.”

Likewise, despite the fact that, due to advances in the medical management of cancer and the fact that people who have been diagnosed with cancer can now often expect to live longer following treatment, there remain relatively few studies of the experience of living with cancer as a chronic illness, particularly from a psychosocial perspective (Small, 2001). In their systematic review of the research evidence into

the psychosocial implications of living five years or more following a cancer diagnosis, Foster et al (2009) concluded:

The purpose of ...[the] review was to explore the empirical literature and establish the evidence base for providing psychosocial support to long-term survivors following a cancer diagnosis in adulthood. In 1998, Gotey and Muroaka demonstrated the difficulty in generating conclusive or general comments from the literature due to the diversity of study approaches and definitions of quality of life and long-term survivorship. Almost a decade on this is still the case. There is still no standard definition of 'long-term survival' (Foster et al, 2009, p 243).

Indeed, in a recent conference presentation, Jessica Corner, made the case for the need for research into cancer survivorship (Corner, 2011). Thus my study, with its focus on enabling people living with cancer to explore this experience for themselves as individuals, not only reflects the founding principles of the hospice movement but could also make a significant contribution to the development of social work practice in an area which both merits and could benefit from wider exploration.

Selection of Research Methodology

As stated earlier, a high proportion of recent research studies in palliative care have focussed on service-led service evaluation and pain and symptom control (Corner, 1996). These subjects lend themselves to a biomedical 'positivist' model of scientific research, in which it is believed that there is an objective reality which can be discovered, measured and understood (Charmaz, 2003, p 84). "Positivism asserts that there is an objective reality which exists independently of our knowledge and of our methods of understanding it and that this reality is governed by laws that can be studied and understood by the use of objective and sensitive methods" (Field et al, 2001, pp 4-5). However, this view has been challenged by academics from a range of disciplines who have argued that its reductionist assumptions create problems in accounting for the role of people in shaping reality, stating that reality is contingent rather than given (ibid, pp5-6). In response, an alternative approach developed,

which can be broadly categorised as ‘interpretivist’ or ‘qualitative’ research (Charmaz, 2003).

The main aim of qualitative research is to go beyond the surface and easily observable aspects of reality to personal experiences and their subjective meanings to individuals. The interaction between data collection and analysis is central to the research process and the qualitative researcher needs to ‘expect the unexpected’. An important aspect of qualitative research is that it may be redirected over time rather than, as in quantitative research, staying rigidly to its original focus and direction (Denzin and Lincoln, 2000; also Charmaz, 2003 and Field et al, 2001)

The differences between qualitative and quantitative research are reflected in the different types of topics studied and range of methods used. The most obvious difference between the two is that the former concentrates on people and their experiences using words rather than numbers as its data. Qualitative research studies are concerned with the analysis of human experiences and subjective meanings and locating these within a social context. “Rather than testing theories and hypotheses they are inductive and concerned to discover new knowledge and to ‘ground’ this in the subjective experiences of their subjects” (Field et al, 2001, p 7; see also later under *Grounded Theory*).

With respect to my proposed topic, it may be deemed possible to adopt a quantitative ‘positivist’ approach by designing a survey questionnaire and asking individuals to explore and reflect on their experiences of living with cancer based on a set of questions on the theme which I would ask to each individual involved. However, my inspiration for this study - my practice experience and my exploration of the themes that have emerged from my earlier case studies - has resulted in a wish to focus on the *individuality* of each person’s experience. I therefore felt that a quantitative ‘positivist’ approach would not be appropriate here because it would have been impossible to pre-judge what those different experiences might be. I did not wish to

limit the scope of the study by pre-supposing the territory to be explored and it would have been impossible to devise 'pre-set' categories and questions because at this stage I did not know what would be the right 'questions' to ask. Thus a qualitative iterative approach, which allows for re-direction and re-focussing as themes emerge, was far more appropriate to my particular research topic.

According to Seale (1998, p17) interpretivists tend to favour qualitative rather than quantitative methods because "on the whole researchers find that people's words provide greater access to their subjective meanings than do statistical trends". My aim has been to focus on understanding the subjective experience of living with cancer and to attempt to derive meaning and develop possible models of social work intervention based on those subjective accounts. Therefore what appears to fit best is an interpretive epistemology in which what is important is how people understand their worlds and how they create and share meanings about their lives (Rubin and Rubin, 1995, p 34). My aim has been to explore the multiple realities inherent in an exploration of experiences and meanings in order to generate rather than verify theory (Punch, 1998) – my research question is one of "seeking understanding", exploring processes and "describing experiences" which, according to Punch (1998, p 19) implies a qualitative approach.

The aim of this research is to generate theory inductively from the multiple realities present in the stories told about lives lived prior to, during and after the diagnosis of cancer and thus to uncover something of the diversity of human experience within this shared reality. I am aware that a criticism of the interpretive perspective lies in the difficulties inherent in making assumptions about the authenticity of subjective accounts in that memory and more recent experience may distort what may be perceived as objective fact by the interviewee. However, the respondents' subjectivity is less concerning here as it is the meanings ascribed to these subjective experiences and subjective truths which this study aims to address (Dodsworth,

2008; also Frankl, 1963). The aim of my study is to explore the differences in both the experiences and the meaning ascribed to them by the individuals who shared their stories with me, and it is crucial that this diversity is reflected in the research process and in the recommendations for service provision that may be made as a result of it.

Qualitative Research Design –Methodologies and Approaches

“Qualitative research is not a unified tradition” (Shaw and Gould, 2001, p 8). Indeed, according to Reissman, 1994, xii, the term qualitative “refers to a family of approaches with a very loose and extended kinship”. There are a number of broad approaches in the design of qualitative research, and in this section I will discuss those which I feel have some relevance to my proposed research study. These are, as follows: ethnography, a case study approach and a grounded theory approach.

Ethnography

Literally meaning “a description of peoples or cultures” (Denscombe, 2003, p84) “Ethnography involves an ongoing attempt to place specific encounters, events and understandings into a fuller, more meaningful context” (Tedlock, 2000, p 455). With the ethnographic researcher immersed in the organisation or fieldwork in question, it can “produce historically, politically and personally situated accounts, descriptions, interpretations, and representations of human lives” (ibid, p 456) based on the assumption that “by entering into close and relatively prolonged interaction with people...in their everyday lives, ethnographers can better understand the beliefs, motivations, and behaviours of their subjects than they can by using any other approach” (ibid, p 456, after Hammersley, 1992). Thus, ethnography can be characterised as being contextualised and largely descriptive, “grounded in the local and particular and ...[making] no over-reaching claims for generalizability ...[A]n

attempt to capture the salient characteristics of a social world without ... interrupting or disturbing it” (Shaw and Gould, 2001, p137; also Bell, 1993, p 10).

In the field of palliative care research, an ethnographic approach was successfully adopted by Hockey (1990), James (1986) and Lawton (2000) to give rich and detailed descriptions of the daily care of dying people in a variety of settings, which included a hospice, a residential home and a community-based service. These undoubtedly give the reader a sense of the ‘lifeworld’ of people who are dying and an understanding of the ways in which their experiences are contingent on the settings and social systems within which they operate (Clark and Seymour, 1999, pp 166- 167). However, despite the obvious attraction of ethnography in its ability to investigate life ‘as it is lived’ by research participants, it would seem to require a more “*holistic approach* which stresses processes, relationships, connections and interdependency” (Denscombe, 2003, p 85) than I felt would be appropriate to my research, requiring as it does a narrower, more specific, individual focus.

Case Study Approach

The case study is also a common approach in relation to small scale qualitative research (Yin 1994). It provides an opportunity for in-depth study of a particular issue, instance or event, addressing meaning in context and exploring detail in a way that a quantitative survey would not be able to attain (Bell, 1993, p 8; also Denscombe, 2003, p 38). Unlike a quantitative experiment, it does not encourage artificial manipulation of a situation, but would seek to study something as it occurs naturally. Its detailed approach draws out the complexities of the issue in question, highlighting inter-connectiveness, examining processes and analysing outcomes (Hollinrake, 2001).

The case study design would seem to fit my research well because it is “defined by interest in individual cases” (Stake, 2000, p 435). It would therefore enable me to focus on the subtleties and complexities involved in the lives of those affected by a life-threatening illness. This approach would likely give rise to a wealth of detailed description of inter-related issues which would provide rich material for analysis. Whilst outcomes are significant, the real interest lies in the processes through which the subjects have come, the meanings they attribute to their experiences and their relationships with others as they explore and reflect on their situation.

However, one of the criticisms which has been levelled against the case study approach, and one which was of particular relevance to my proposed study, is the fact that the onus is on the researcher to select the area for study and to decide what material to present, thus making it possible to distort the focus away from that which the research participants intended (Bell, 1993, p 9). Similarly, since by its very nature the focus of a case study tends to be narrow and contained within relatively distinct boundaries, its scope is limited, making it almost impossible to generalise the findings (Denscombe, 2003, p 39). However, perhaps the most compelling argument against the validity of the case study approach for my particular purpose is the difficulty it may represent in terms of negotiating access to an appropriate setting. The ethical difficulties inherent in conducting research in health care settings, and in particular in the area of life-threatening illness, will be discussed later in this assignment, under Access and Ethical Issues, but the access requirements of a case study approach in terms of my research topic may be impossible to meet, and would thus preclude the adoption of this approach for my study. Moreover, the respondents in my particular study, focussing as it does largely on the experience of those who have completed active treatment, were not necessarily still connected in the same direct way to a health care setting as they would have been at an earlier stage in their illness – and it was this post-treatment phase that was of particular interest to me.

Grounded Theory

According to Scourfield (2001, p 64; after Strauss, 1987) grounded theory is not specifically a technique but rather “a methodological orientation that seeks to base theorising in the data rather than imposing a pre-determined hypothesis.” “Its claim is to be an approach and set of methods for developing theories, concepts and hypotheses direct from the data rather than a priori assumptions...” (Shaw and Gould, 2001, p36). “The grounded theory emphasis on studying processes moves research away from static analyses. We emphasize what people are doing, an emphasis which... leads to understanding multiple layers of meanings of their actions” (Charmaz, 2003, p 90) Thus already the applicability of this approach to my particular research topic is evident, based as it is on subjective meaning and induction of theory, grounded in the emerging data, rather than on a pre-conceived hypothesis (see earlier, Selection of Research Methodology)

In essence, the grounded theory approach begins with the identification of the topic or question the researcher wishes to explore, and data is collected about what people who have relevant experience of this topic say about it (Charmaz, 2003). The researcher may begin with a specific interest in the subject and a set of general concepts which ‘sensitise’ her (Blumer, 1969) to look for certain issues and processes, but it is of paramount importance that she remains open to new concepts, views and ideas as the research progresses – the initial concepts should serve as *points of departure* for developing, rather than restricting or limiting, ideas. Thus it would seem an appropriate method to choose for my research topic – I am already sensitised to it by my experience as a practitioner in the field of palliative care, but am particularly interested in how research participants define their individual

experiences for themselves. Furthermore, adopting a grounded theory approach would enable me to draw participants from a wider 'pool' than that necessitated by a case study, which may solve some of the access issues previously identified. What would be of utmost importance would be my ability, whilst acknowledging my prior experience of practising in this field, to remain open to new concepts and discoveries about the experience of living with cancer (see also later in this chapter, under 'Data Collection and Analysis' and 'Limitations').

The grounded theory approach lends itself particularly to the study of individual processes, interpersonal relations and the reciprocal effects between individuals and larger social processes, with the emphasis on personal experience, emotional issues and issues of identity (Charmaz, 2003 p 83). Charmaz has successfully applied this approach to her study of the experience of people living with chronic illness, which has obvious relevance to my own choice of research topic (see also earlier, *Biographical Disruption and Identity*, in Literature Review). Of particular note in the context of my choice of research method is the fact that the 'creators' of the grounded theory approach, Barney Glaser and Anselm Strauss, developed its methodology in their seminal study into issues of communication and patients' awareness of dying (Glaser and Strauss, 1965), thus signifying the relevance of this approach to research into end-of-life care (see Field et al, 2001, p 15). Furthermore, according to Shaw and Gould (2001 p 56) grounded theory has continued to be both active and influential in general social work research.

Thus I felt that the grounded theory approach was most suited to my choice of research topic. In the next section I will explore particular issues regarding research design in relation to my particular research topic.

Data Collection and Analysis

Of the different methods of data collection available to the qualitative researcher, for example, questionnaires, interviews, observations and the use of documents, I chose to conduct a small-scale study using in-depth semi-structured interviewing as the main method. According to Darlington and Scott (2002, p 48) “In-depth interviewing is the most commonly used data collection approach in qualitative research” and I felt this would be appropriate in terms of my chosen topic, which requires detailed insight into the psycho-social worlds of people living with life-threatening illness. According to McNamara (2001, p 15), who has drawn upon a variety of data collection methods in her research into various aspects of death and dying, “...interviews with dying people ...give a more intimate understanding of how people actually think about approaching death. While the survey study indicates trends in public opinion about dying and death, the face-to-face discussions collectively portray the uncertainties and changing circumstances of dying people and their families.” Although my subjects were talking about living with cancer, rather than dying from cancer, I felt that the issues McNamara raises about face-to-face interaction applied equally to my study.

Interviews

Research interviews and social work interviews share a similar skills base. The counselling skills of the interviewer (Egan 1986) play a significant part in achieving a relationship of trust which is likely to yield meaningful data and a high degree of self-disclosure on the part of the interviewee. Gilgun (1994) notes the similarities between the skills of a social worker and those required to conduct qualitative research (also Hollinrake, 2001). Certainly I feel that my practice as a Social Worker in palliative care has equipped me for the role of qualitative researcher, for example, through the development of advanced listening and communication skills and a person-centred empathic approach (Shaw and Gould, 2001, p 142).

Likewise the 'use of self' which I feel has categorised my social work practice, involving as it does a process of self-awareness and reflexivity in the process of understanding the client's world, which may connect with my own but at the same time is recognised as being unique and different (Fook, 2001, pp127-128) seems to accord well with the quality of in-depth interviewing required by a qualitative research design.

It is, however, important to recognise interviewee distortions and defences which may arise from the interviewee's perceptions of the power differential between themselves and the interviewer (Darlington and Scott, 2002, p 51). Critics have questioned whether it is indeed possible ever to achieve a true account through the interviewing process and Toukmanian and Rennie (1992) maintain that in unstructured interviews "regardless of how much the interviewer may wish not to influence the course of such an interview, the fact remains that it is co-constructed by the interviewer and interviewee" (1992, p224).

Feminist researchers attempt to resolve this issue by making their agendas and potential biases explicit (Oakley 1981), and by involving themselves very directly in the interviews, in order to establish sufficient trust with the interviewee to encourage them to 'open up' (Hollinrake, 2001). This modus operandi would again seem to accord well with my preferred method of social work practice, which is the person-centred 'casework' approach (one which is by and large still practised within social work in end-of-life care, as described in my Literature Review). It also reflects the concept of the 'human-as-instrument' described by Lincoln and Guba (1985), in which the researcher's skills, experience, background and knowledge are made explicit throughout the research process.

It is important in any case to be clear about the researcher's position within the research process. Whilst my own knowledge and experience cannot be discounted and was, I felt, useful in sensitising me to the topic, I counterbalanced this with consultation in the early stages of my research with two people who were 'living with cancer' to assist me in identifying, refining and gaining a more sensitive understanding of appropriate questions for the interviews. The questions I anticipated asking at this stage were open, inviting the participants to 'tell their stories', with the aim of eliciting their own definitions of significant areas of interest, but prompting along the lines of 'How did you feel when you were first told your diagnosis?', 'How do you think things have changed now?' and 'How has it altered your approach to life?' Although the use of unstructured interviews would seem to accord well with a pure grounded theory approach, I felt that the use of semi-structured interviews would more honestly reflect the prior knowledge and assumptions I had gleaned through my years of practice with this service user group (Shaw and Gould, 2001, p 143). I was also aware that, as I had now chosen to focus my study on the experience of 'living with cancer', the themes that would emerge would be less familiar to me, as my practice experience had tended to focus on people whose life-expectancy was more limited.

Although Lincoln and Guba (1985) suggest that taping interviews can lead to distrust on behalf of the interviewee, I decided to record and then transcribe the data collected, since an alternative method of writing notes during the interview would seem to me to detract from the immediacy of the situation.

Access

My situation in terms of access to this client group changed since I first began formulating this research proposal, in that I no longer worked at the Hospice but had

taken up an academic post in a University Centre for Social Work. Likewise, in recognition of advances in the treatment and management of cancer, which has resulted in more people living longer with the disease, the focus of my study has also changed, from exploring the experiences of those dying from cancer to focussing on those who are living with it. Although I had originally intended to conduct interviews with service users in the agency in which I was working, I now see that this could have been problematic, in that patients may have felt pressurised to participate in my study in order to please me or to ensure a good service from me in the future. Indeed, Padgett (1998b) argues strongly against practitioner research of this nature: “Qualitative research is incompatible with the practice mandate when the practitioner is also the researcher” (p 37), since, she argues, “the loss of critical distance” which the practitioner- researcher role implies can lead to the “erosion of rigour” (p.11). Although this somewhat unequivocal view has been called into question (Shaw and Gould, 2001, p 162, also Riessman, 1994, and Gilgun, 1994), I feel I am in the privileged position of being able to apply the good practice I developed as a palliative care social worker to my research in terms of interview technique, without the ‘complication’ of being involved in direct work with potential respondents.

Having considered the idea of approaching former colleagues within the Hospice and palliative care movement, to ask them to identify patients who they feel would be suitable respondents for this particular research topic, I felt that this approach was too limited, in that it would have been unlikely to yield the richness and variation of data I desired. How, indeed, would the professionals deem a potential respondent ‘suitable’ for this type of research? In order to avoid the danger of only interviewing patients who are particularly interesting to professionals, I decided to broaden the scope of my research by approaching a local Self-Help Group in a different region to the one I was living in, which I had been made aware of through a former service user but with which I had no direct involvement, and which comprised individuals who were living with a diagnosis of cancer, but who met outside of the confines of

the hospital environment in order to support each other without professional involvement.

Addressing Limitations

I recognised, however, that respondents drawn from such a group may represent a slightly biased, self-selected population made up of people who have opted to seek the support of others, and I acknowledge the potential this may have to skew the findings. In order to minimise this, I adopted a network or 'snowball' sampling approach (Lee, 1993, p 65) to identify individuals who are living with cancer, who may be known to the original respondents, but who may not have chosen to join a Self-Help Group. In order to increase the diversity of the study, I added to my respondents individuals I met on conferences (both delegates and facilitators), and relatives and friends of people known to me who were aware of my study, thus widening the pool of participants in a variety of ways, including by geographical location, class, age but sadly not ethnicity, which I acknowledge is a limitation of the scope of the study. Discussion around sample size for in-depth qualitative studies seems to indicate that 20-25 interviewees is the maximum number (Douglas 1985), though I would agree with Lincoln and Guba (1985), who argue that saturation point can be reached with as few as 12 participants (Hollinrake, 2001). I therefore struck a 'happy medium' by conducting 18 interviews, which I felt would give me sufficient data within the grounded theory approach.

It will also be noted that I have re-considered my initial proposal to interview female respondents only, and have broadened the focus of my research to include both male and female respondents, as I feel this is more aligned to a grounded theory approach which sets as few restrictions as possible on themes which may emerge. For similar reasons of not wishing to pre-judge emerging themes I altered the focus of my initial

research question to include an exploration of all aspects of the experience of living with cancer, and not just the potentially positive ones. The only stipulation I made was that potential respondents should be adults over 18 and at least one year post-diagnosis, as I feel that adults would be likely to be able to conceptualise their experiences in a different way to children and young people, and that interviewing people at an earlier stage following their diagnosis may be too soon to have allowed sufficient time for reflection on the experience.

Ethical Issues

My proposal received the approval of the University Research Ethics Committee but, because I chose to draw my sample from a variety of sources outwith the hospital environment, I was advised that it was not necessary to seek the permission of any other Research Ethics Committees. I fully understand the importance of working to ethical guidelines, noting with Payne and Field (2004, p 55) that "...principles and professional guidelines for ethical research practice are well established and should ensure that people are free to make informed decisions and are protected from exploitation." However, I am also aware that there is an understandable tendency on the part of ethical review boards to be 'over-protective' of people construed as vulnerable, which doubtless includes people who are living with serious and life-threatening illness, reflecting as it does societal discomfort about death and dying (see Lee, 1993, also Payne and Field, 2004, p 54).

In order to enable potential participants to make an informed decision as to whether or not they took part in the study, I gave them as much information as possible prior to them making the decision. Letters were sent to potential participants to explain clearly the purpose and intent of my research, my role and relationship to their group and my plans for the dissemination of findings, including feedback to respondents.

Likewise consent forms were designed to give potential respondents another opportunity to decide whether or not they participate, and it was emphasised that they have the right to withdraw from the research at any time (Boynton, 2005; also Payne and Field, 2004, Smyth and Williamson, 2004).

According to Corner (1996, p 203) “there remains a degree of ambivalence over the necessity and morality of researching the dying.” According to Payne and Field (2004 p 52; after Parkes et al, 1997) “Many cultures have sensibilities about open acknowledgement and discussion of death ... which serve to confer upon those who are facing these life transitions a special status of vulnerability and an expectation that they should withdraw (and be protected) from ...social engagement.” On the other hand, it has also been argued that, in the pursuit of best quality palliative care, research in this area is not only desirable, but a “moral imperative” (Corner, 1996, p 203, after Speck, 1996). Similarly, Cassaret and Karlawish (2000) make a case for equal opportunities, arguing that dying patients should be given the same opportunities as other potential respondents to choose whether or not they participate in research studies. Although my study was not so much about dying but living with cancer, I feel that the same ethical considerations apply.

However, while I would adhere to the latter argument, that potential respondents should be given the opportunity to participate in the study, whatever their status, I would see it as imperative to develop a strategy for referring interviewees on for further assistance should particular emotional or practical problems emerge. Notwithstanding the potentially cathartic effect of ‘telling one’s story’(Lee, 1993, p 21), the discussion of emotional issues and/or deterioration in the physical health of individual respondents may provoke the need for such support, or , in some cases, the withdrawal of the participant from the study altogether. This has obvious implications for the possibility of theoretical sampling, but it was hoped that the sample size would ensure that sufficient data will be gathered to ensure that this does

not have a significant effect on the study as a whole. In fact, no respondents withdrew from the study.

Issues of confidentiality were addressed by the assurance of anonymity, and the fact that the identity of participants would not be revealed in any deliberate way.

I am very much aware of the difficulties inherent in gaining ethical approval for research in this area and hope that, by being transparent about my ethical position and demonstrating my awareness of the vulnerability of this client group in my submissions for ethical review, as well as providing evidence of the measures I put in place to protect respondents, my acknowledgement of these considerations will be seen to be sufficient (see Payne and Field, 2004, p 55).

Data Gathering

There were 18 participants in my study, whose ages ranged from 38 to 76 at the time of interview. Identifying and obtaining the sample and conducting the interviews extended over a time period of approximately two years, due to the fact that my postgraduate research was conducted on a part-time basis. Although this was a relatively long time period, as grounded theory had been chosen as the approach for analysis, it was possible for initial analysis to begin from the point of transcription of the first interview. The iterative process of data collection and analysis was crucial in shaping and adjusting the questions I went on to ask in later interviews and the development of the final analysis, as it was possible to pursue themes from early analysis in later interviews whilst still ensuring that there was sufficient freedom for new stories to be told (Dodsworth, 2008, unpublished thesis).

Developing the Interview Schedule

Crucial to my study was to understand what differences (if any) the experience of cancer had made to the respondents' lives, and therefore I needed to develop an interview schedule which would seek to ensure that a chronological route was taken through the lives of the respondents from first realising that 'something was wrong' and seeking medical attention, through diagnosis and treatment on to current feelings and new perspectives on life, work, relationships with self and others and so on. The overall aim was to provide an outline structure which also allowed for flexibility within the interview to ensure that space was given for respondents to tell their own individual stories, the variations in which would provide the codes and themes to inform further interviews.

An interview schedule was devised which addressed the key areas I wished to cover in the interviews, but open questions were used within a person-centred approach which enabled a degree of flexibility of interpretation and meaning by individual respondents. The questions were designed to explore the chronological journey of the respondents through their personal experience of cancer. I chose therefore to use a semi-structured format for my interviews (Paton, 1990) rather than an unstructured approach, as I felt this was more likely to elicit answers which focussed on the research question, while retaining the potential for individual interpretation and which could be analysed according to a grounded theory approach.

Supplementary questions differed from interview to interview, as it was important that individual respondents were able to emphasise the aspects of their 'journeys' which had particular resonance for them. As I explained previously, the skills I had learnt as a social worker were useful in establishing rapport, empathy and trust and in sensitising me to the material, but also in establishing me as an "acceptable outsider" (Sanders, 2005).

I was careful to reassure participants about the purpose of the study, which was not only to increase public awareness of the issues facing respondents, but also to inform professionals in the field in order to improve future service provision for those living with cancer. This was intended in some way to redress the power imbalance between interviewer-interviewee, by recognising the expertise of the respondents as service users, whose views have not always been taken into consideration when planning services (Beresford et al, 2007).

I relied on my social work skills to monitor and ensure the well-being of the participants. Some of the interviews did prove to be difficult for some of the participants: a few became tearful when recalling painful memories. I was careful at these points to review the interview schedule, to ensure that people had the opportunity to tell all the aspects of their story that were important to them, without being intrusive or unnecessarily evoking painful memories. I always stopped recording at these points and 'checked out' with the respondent whether they wished to continue with that particular theme, or with the interview as a whole. In every case, the individual expressed a wish to continue, which I feel demonstrates a congruence between their behaviour in the interview and 'normal' regulating behaviour observed in people living with cancer, where emotions can oscillate between a restoration orientation and a loss orientation (Exley and Letherby, 2001).

The interviews were generally of one and a half hour's duration and the majority took place in the respondent's own home, although several respondents chose to be interviewed in their workplace, and one chose to come to my place of work. The interviews were (with the respondents' permission) tape-recorded and later transcribed by a professional colleague. As soon as possible after each interview I wrote a short synopsis of the interview, thus briefly noting emerging themes and hypotheses, and my immediate thoughts and feelings, which I would then use to inform my next interview. This reflection formed an essential part of my ongoing

analysis of each transcript, and ensured that any new emergent analytical categories were captured for subsequent analysis in an iterative process in which the data informed the emerging analysis, which in turn informed the data collection and final stages of the analysis.

The unit of analysis were the words transcribed from the tape recordings. Using the coding and memoing techniques of grounded theory, I sought out patterns and themes within individual accounts, connected them across a group of interviews and therefore built theoretical categories as they arose from the individual narratives. “The grounded theorist’s simultaneous involvement in data gathering and analysis is explicitly aimed toward developing theory... Grounded theory interviewers adapt their initial interview guides; they add areas to explore and delete extraneous questions” (Charmaz, 2003, p 89 - 90). I chose to use the grounded theory approach to data analysis over narrative discourse analysis as I was particularly interested in the individual experiences of potential respondents, rather than analysing the words that they use to describe those experiences.

Line by line open coding was undertaken on each transcript as soon as possible after each transcript was delivered. Punch (1998) describes coding as both a specific and concrete activity which starts the analysis, but also *is* the analysis, in the sense that advanced coding applied at higher levels of abstraction of the data forms and informs the analysis. The first level or ‘in vivo’ codes arose directly from an inductive ‘drawing out’ of concepts from the words of the respondents. Subsequent axial coding was more interpretive and selective, and some detailed codes became subsumed into larger and broader code categories as key patterns began to emerge. I chose not to use an electronic data analysis programme (NVIVO or NUDIST), but instead to work with paper copies of the transcripts, which I physically cut up and placed in different piles according to the codes. This enabled me to remain closer and to be more sensitive to nuances in the data.

Gradually a story began to build from the individual narratives which was characterised by both similarities in terms of the experiences themselves and differences between the individual responses to them. I used a 'zigzag' process (Creswell, 1998) to code and recode until I felt that saturation had been reached in terms of the emerging categories, and I was able to begin to form wider groupings which eventually became the themes outlined in the next chapter of this thesis. I continued to read and re-read the transcripts in their entirety to ensure that I retained the individual stories of each participant, recognising that, while 'fragmenting the data' (Denzin and Lincoln, 1994) is an essential element of the grounded theory approach, I wanted to be sure that the themes that seemed to be emerging were representative of the stories told.

Analysis is, as Coffey and Atkinson (1996) note, a cyclical and reflexive process. Indeed, as Becker (1965, p 602), cited in Roberts and Sanders, 2005) notes: "No matter how carefully one plans in advance the research is designed in the course of its execution. The finished monograph is the result of hundreds of decisions, large and small while the research is underway".

In this chapter I have attempted to analyse and describe the choices of methodology available to me as a researcher and to explore some of the issues which are specific to my chosen group of respondents, in order to select the best method for this particular research topic. For the reasons I have given I have decided upon a qualitative research design, noting its relevance for this particular topic, and to adopt a grounded theory approach which I trusted would give me rich data to explore. According to McNamara (2001, p viii) "despite the disorderly manner in which people die... patterns can be found in the way that we approach dying [or living with dying]..." It is these patterns that I hoped to discover, and to work with them in a

sensitive manner to the benefit not only of individual respondents but of future service users and of society as a whole.

The following chapters will explore the ways in which differences and similarities emerged from the data. Quotations have been used extensively to ensure that the voices of the respondents and their individual stories are heard, and I have sought to ensure that everyone who participated has a voice in this final version.

THEMES

I have organised the themes that emerged from my analysis of the data collected in my interviews into a sequence which seeks to follow the chronological journey of a person who is given a diagnosis of cancer. This ‘journey’ is that taken by the respondents and narrated by them in my interviews with them, as they followed the semi-structured interview schedule, from the point of first realizing that something was ‘wrong’, to seeking medical advice and intervention, to exploring the effects that this had on themselves and their relationships with others and finally their perspectives on life and their ‘new’ place in society, as well as their recommendations for future policy and practice. The core categories and sub-themes that emerged from each interview, and which informed the supplementary questions I asked from one interview to the next, are explored in this section, using the respondents’ own words. The following section ‘Interpreting the Findings’ will expand on these themes in relation to the literature already reviewed in Part One and to further studies which became relevant as the themes emerged.

Although eighteen respondents were included in my study, and all have a voice within this chapter, I have used the words of certain characters to a greater extent than those of others, as these can be seen to be representative of the themes which emerged. A key to the respondents is included as Appendix 1 to this study.

Medical Engagement

This in many ways represents the first stage of the journey, the involuntary entry into the ‘new’ world of the cancer patient. Respondents were encouraged to recall their lives before they were diagnosed with cancer and to describe what – or who – it was that first prompted them to seek medical advice, to bring to mind their initial realization that something was wrong. Despite the fact that there was often a significant delay between acknowledging that things were not right and actually

seeking medical advice, all the respondents can remember with extreme clarity their first encounter with the medical profession, the point at which the bad news was broken, with many being able to recall minute details of the place, the people and sometimes the very words that were used. Issues of the relative power of patient and professional are explored. The encounters are experienced as variously positive and negative, and respondents are able to offer suggestions as to how the breaking of the news might have been done more sensitively or effectively. They speak of the on-going treatment they received from the multi-professional team and how much they felt they were or were not involved in choices about their treatment. Issues of health promotion and potential inequalities are discussed, particularly in the light of behaviour seen to have an adverse effect on their health and their ability to respond to treatment, for example, smoking.

The fear of cancer and the myths that surround it, both in the minds of the respondents and those of the people around them, are acknowledged and explored.

Breaking Bad News – Becoming a Patient

For David, as for a number of respondents, the moment of diagnosis is imprinted on his mind: "...it is a marker of the significance if I tell you it was the 18th August 1995...It is imprinted. Here we are 13 years later and yet I can still remember the day...it is so indelibly marked when it comes straight back to you like that..."

David had noticed some problems with his health but had attributed them to his lifestyle and employment, the stress of the workplace and the feeling of being indispensable, of not wanting to let others down:

....you have to...contextualise, I was a teacher working in a unit with disruptive pupils and it wasn't unusual to lose your voice, it wasn't unusual to pick up infections because you were constantly in a group that was passing things around. So sore throat for a teacher and for someone who was a smoker wasn't unusual. My voice started to go and again when you are analysing and looking for a change in the future you can see with hindsight the changes and you can understand them, but at the time I was thinking "I don't have time to go to the doctor"...So you think "I will struggle on". This was at a time of Ofsted inspections just starting to move into that area of

work...Of course at the time as an individual your throat is getting bad and you are smoking and you are not really having that sensible balanced view.”

In the end for David it took the intervention of a colleague to ‘shock’ him into seeking medical advice:

My voice continued to go ...and it was not getting any better and a friend came into a workshop I was running on Saturday morning and heard my voice and said ‘[f]or goodness sake get to the doctor, I think there is something serious there’...So fortunately because he hadn’t been around for a while he could then hear the huge change rather than the subtle change...The doctor took it seriously and referred me to the hospital...

A number of respondents speak at length about issues of communication and how the news of their diagnosis was delivered to them. David offers a rather surprising interpretation of what might in other circumstances be deemed to be rather poor ‘indirect’ communication:

So my appointment... was probably August and I went along and I was very fortunate because I had a junior doctor...who looked down my throat to begin with and he tried again and he went ‘oh, ah, oh’. In some ways for clinical practice it is not good, but actually in its own way those non-verbal noises were significant and he then said ‘would you mind if I got the consultant to have a look?’. So he then left the room and my wife and I were left together...That little non-verbal thing gave you a sense and we turned round and said ‘it probably is cancer’ but actually it was almost a relief because I had it confirmed.

David’s expression that it was ‘almost a relief’ to receive confirmation of the diagnosis of cancer coupled with the reassurance that some form of treatment might be possible were characteristic of a number of the respondents’ accounts. The sense that the experience was not entirely negative was again not uncommon, and many saw the doctor or more usually the hospital consultant as knowledgeable and powerful and there was the sense of being ‘in safe hands’. Although David was obviously quite powerful in his own profession, he was glad in this context to give power to the medical team, feeling reassured that they took control. However, he had the particularly positive experience of the team working together effectively in consultation with him as the patient, although he appreciated that this was not the case for everyone:

the decision-making was done in a multi-disciplinary fashion at the time where the surgeon and the oncologist were there and it was a really good debate about whether it was to be a laryngectomy or radiotherapy, the surgeon said he would rather do a laryngectomy ... the oncologist said, he took my hands in his hands and he said, we are doing radical, intensive radiotherapy with the intention to cure'..and it...fixed the words in my head...So...he had taken my hands in his hands in a metaphorical and a literal sense and that again was a powerful vehicle for me, I was looking for the symbols, so in that sense I could see what was actually happening...because what the surgeon said was 'I trust my colleague implicitly', if he says he can do radiotherapy he can.

However, despite the positive aspects of his treatment, David still experienced some of the pain of cancer and its treatment and the fear associated with it, fear not only of what was happening in the present but of how the future may be affected, an aspect which again characterized a number of accounts:

You say that I had a good rapport [with the medical professionals] ...yes I did, but it doesn't take away from a very frightened and scared individual...It doesn't take away from the very belief that I was going to die and that it was going to come back and move about my body and it took a long time for that to go away

For Bill, the realisation that something was wrong was brought home to him by the 'new' experience of a different type of pain. His account, however, is characterized by phrases such as 'lottery' and 'chance', suggesting a sense of everything in life, including his health, being unplanned and out of his control:

I just knew, I just knew because the pain that I had was just a pain I had never experienced before and I kept going back to the doctor and they kept fobbing me off and it was only by chance, I think this is where there is very much a lottery, it was by sheer chance that I was diagnosed ... It was only in desperation that I went to the doctor's and said 'no, you need to do something, I can't eat'. I had oesophageal cancer and I couldn't even touch it myself, it was so sore...so they sent me for an endoscopy and I knew anyway.

Bill expressed very clearly what his experiences of engagement with the medical profession have taught him, reinforcing his sense that it is a lottery :

It is difficult because, having experienced what I have experienced, the good, the not-so-good and the downright negative aspects of the health service, of treatment, of people's attitudes, that has only cemented my proactive stance, because I think that, without being disrespectful, the health service is very much a lottery...

Robert had known for a number of years that his health was compromised: he had a blood condition which was a form of cancer which had been discovered while he was undergoing health tests when he and his wife were trying to conceive their first child:

I was told in a very kind of blundering way by a doctor who had never seen me before so I was quite annoyed about that but because my attitude was fairly relaxed anyway and I knew that the condition didn't have short term devastating consequences...[the consultant] ...told me...that it is quite unusual to have the condition at my age [but]... that he thought that it didn't necessarily shorten my lifespan... so after some exploration and confirmation I just sort of plodded on and had six monthly blood tests...I then came off the medication [in order to for partner to conceive]...and after that decided to not go back on it

However, in 2003, Robert was told that his bone marrow was deteriorating and he was diagnosed with myofibrosis, and told that the only cure was a bone marrow transplant. He speaks of the confusion of symptoms that he experienced, of how he was given conflicting advice by different medical professionals and of the need to know what was actually wrong with him, both for himself and for those around him:

After that very strange things started to happen...I had these post viral symptoms which put me into essentially a long term sickness position in terms of my work and so I stayed off work throughout the summer...That summer was a very confusing time because I was getting confusing advice from my GP and the hospital which didn't help at all, my GP was saying quite consistently 'look, this is my experience and I have treated people with the same conditions and this is to do with your underlying haematological problems...[but] the consultant was saying categorically that there was nothing in the tests that they had done...which showed any account for the symptoms I was having...I didn't know who to believe and so I decided, well, I went with the consultant because I think at that stage in an illness like this you need to know what is wrong with you...

Robert struggled with not having a diagnosis and so formulated one for himself, one which did not have the same ‘negative’ connotations as cancer (See Chapter One, The Special Case of Cancer):

So what I had decided was that these symptoms I had were ME because it totally fitted with ME, it was to do with what I knew about ME...and also the way the illness came on. So I stayed off work and also had an occupational health consultation, they were very good and he also took my line I think and quite rightly really, that it was symptoms of ME ...

Kate’s diagnosis with cervical cancer at a relatively young age was further complicated by the fact that her father was dying from cancer at the same time, and that her mother had already been diagnosed in the past. Kate’s diagnosis came as a surprise to her but, on reflection, she realises that her symptoms may have been masked by the amount of stress she was experiencing in her personal life:

Basically I didn’t know there was anything wrong with my health, the only thing I did notice I suppose, because I was 36 when I was diagnosed, I was going through quite a bit of emotional stress, I was married.. and my husband at the time did have a drink problem and I think that affected me emotionally, so I was aware of that. I had always been fit and done fitness classes, I used to be a professional skater so I had always looked after that side of my health, but I think the emotional side had affected my eating habits, so my eating habits, if I get a bit upset or whatever then I go off food. So that was maybe the thing I think that I probably worked more because I felt stressed...It is strange in a way in that in some ways I guess it is a shock, it’s a surprise, but in other ways it wasn’t, it seemed like two sides of the same thing, it was quite strange.

Kate’s sense of shock was exacerbated by the news that the cancer had spread:

I was told that I had been diagnosed with...cancer of the cervix and so I had a hysterectomy and thought, right, I will have the operation and that will be it, basically but I think the surprise was that, after I had the operation, I found out that it had spread and I think that was quite a big blow really because I wasn’t sure what was going to happen of course...

Kate opted for conventional treatment but combined pioneering avant-garde medical treatment with complementary self-help techniques which gave her the feeling that she was regaining some control over what was happening to her body:

I started off with a cone biopsy and then I had a hysterectomy and then after that because the cancer had spread I first of all had radiotherapy. Dr C had only just returned from America at that time and a way of treatment over there hadn't been used over here and so he was using me as a bit of a guinea pig in the sense that he was using a system that he was working somewhere else... I had read a book...called Getting Well Again and it was 2 doctors in the States and basically how they taught or helped cancer patients to get visualize while they were having treatment. There were different ways of doing it and you had to find a way that worked for you... what I used to do was a bit of meditation before I had the treatment and then sort of talk to my body and talk to my cells and say 'look the cells that don't need to be in the way that are fine and healthy and that have no cancer in them, you have got to move out of the way, you have got to stay safe'.

For Faye, it was some time from initially suspecting that something was wrong to actually seeking medical advice. It was the acknowledgement of a friend's experience of cancer and of her husband's anxiety about her (Faye's) health that eventually prompted her to seek help.

It was January 2003 that I was diagnosed, but I actually found... I found the lump probably in January 2002 actually. Basically I had a pain in my breast every morning when I got up...which is not actually a characteristic sign of breast cancer. But a really good friend of mine who is the same age ... had just been diagnosed with breast cancer the Christmas before... I ignored it for about six months but my husband was getting really cross with me because he said 'you keep saying you have got this pain, I want you to go and get it checked' and I just thought I was being over dramatic, you know, because I had a friend who had breast cancer and she was having her chemo and I just thought it might have been psychosomatic.

However, when Faye did seek help her fears of cancer were summarily dismissed by the GP who did not take her concerns seriously, despite the fact that she [Faye] did have some knowledge of breast cancer and the fact that it can affect younger women, both from her own profession as a physiotherapist and from the experience of two of her friends. Nevertheless, she deferred to the medical professional, possibly because she was telling her what she wanted to her: that she could not have cancer.

I did then actually go to the GP and I had a young female doctor who said to me that I was too young to have breast cancer and not to worry about it and then I thought 'well, actually I have got 2 friends who are the same age as me and both have got breast cancer. She looked at me a bit like I was stupid and I was a physio so I have quite a bit of knowledge and I remember saying

2 or 3 times that they had breast cancer and she said ‘no, no, no, they are too young to have breast cancer’ and I said ‘no, they have breast cancer’ because I just thought ‘don’t tell me’ you know? ...Anyway, so I sort of went away and ignored it but I could feel a pea sized lump, but the thing was I had this pain to direct me and I was fiddling so much I wondered whether I had caused it.

It was the intervention of another member of the medical team who eventually took action with regard to Faye’s lump, but even then the original doctor seemed reluctant to change her original opinion. Faye demonstrates a very open and forgiving attitude to the medical profession in giving the doctor a second chance, but is able to challenge the power of that person and be assertive enough to press for an appointment, spurred on by the fact that a close friend of a similar age was already undergoing treatment cancer:

It was then about 2 or 3 months later when I went for a smear and the nurse said to me ‘do you check your breasts? And I said ‘well I do and I have this lump’ and I sort of told her what had happened with the doctor and she said ‘well, I don’t think that is acceptable’ she said ‘while you are here, go round to that desk and book another appointment’ and I went ‘ok’. She was great actually and I think she saved my life partly. So I went round and made the appointment and got the same doctor again... and she sort of said ‘well I have told you before that I don’t think it’s breast cancer and I can’t feel anything, but you have come back to me twice so I am going to have to refer you’...and I said ‘if there is nothing there, there’s nothing there, but I would like to get it checked’.

Diagnosed with breast cancer and having agreed to an excision, Faye underwent the operation with a very positive attitude and was genuinely shocked to find out that the news was not good:

I was in such a good mood and I was laughing about not having eaten because of the pain killers... and then the doctor came in with this nurse and I still didn’t twig, whereas I don’t know whether [husband] did... Anyway, he came in with this nurse and sat us down and...well basically he just came straight out with it. He just said ‘well, we were all really shocked with your results because we were all certain that your lump was just a lump and actually it is breast cancer’ and I remember feeling like someone had punched me in the face...

Mo was also initially reluctant to seek help but was prompted to do so by her husband:

It was actually my husband that felt a lump in my breast and the initial feeling was that it was nothing, there was nothing wrong, but he pushed me to go to the doctor and then follow it up. The doctor didn't think there was anything and it was a case of 'it will go' so we did actually have to push to get the results back and to get a referral...going to the doctor was very quick ...and then we were told that they would refer me to the consultant..

Jean had also anticipated that something serious was wrong, and had conjectured that it was cancer:

...from the October the year before there was blood in my urine occasionally...I didn't worry too much about that because I had had some womb problems in the past and that had been a factor so I was using oestrogen...but then what started was I was having to go to the toilet frequently and also I sometimes got caught short and it was then that I started to get concerned about it...they tested first for a urinary infection ..they did that twice because they weren't sure...during that time I had looked it up in my trusty Macmillan Health Encyclopaedia and I did say to the doctor, who is a really nice doctor, that it could be cancer couldn't it and he said 'well, we don't need to go down that road now' but friends did remark when it was diagnosed 'well, you did have an idea that it might be'...

Jean appreciated that her request for information and counselling support was met at such an early stage in her illness: "So I was taken back into the ward to recover and I said to one of the nurses 'I need to know more about this' and they sent me a nurse who was a nurse counsellor and from that point on I had their phone number and I could phone them up anytime..."

As a trained counsellor, Jean had a good awareness of effective communication and, because of her experience, was able objectively to assess the doctor's communication skills in her consultation with him.

As a counsellor it was quite interesting watching him gauge how much I really wanted to know and I kept saying I want to know what the possibilities are and in the end he actually drew me a picture, told me that they would be taking a biopsy and what that would involve and gave me his phone number, drew me diagrams and gave me the number of [support service]. There was a bit of me who was quite interested in how he handled me because he was all the way along watching to see did I really want to know this ...and I did...

Fiona's previous experience of cancer prompted her to seek help – she had felt that it was inevitable that she would get cancer because it was very common in her family and also that, because her cancer was not deemed to be life-threatening, she had had a 'lucky escape':

I did have a hysterectomy and it was because they had found cancer cells. That was in 1984, but they got it all away and so that was good...there seemed to be a cancer gene within my family. There have been so many many people on my mother's side that have had cancer, all different cancers, not just the same one. It seemed something that could be provoked, put it that way, not that I was definitely going to get it, but I was a candidate if I had got too much stress...so I had the hysterectomy and they tested all that they had removed and the cancer hadn't returned so I didn't need any more treatment... that was in 1984... I thought I was lucky, cancer had taken its swipe at me

However, Fiona went on to develop further health problems, which were initially attributed by the GP to stress:

He got up from his chair, walked around the back of my chair, got hold of my head like that, lifted me up from the chair with my head and twisted my head that way and that way and said 'it is stress, look at you, you are just stressed out. What are you stressed about?' And I hadn't a clue, I didn't have anything to be stressed about..."

S So everybody was focusing on that side of things, the sort of emotional, psychological side of it rather than anything else?

F I was a woman who was into her 60s, pension age, feeling sorry for herself...

It took nearly a year before it was actually diagnosed... they said I had 6 months to live and I should go home and let nature take its course...

Fiona was aware of what she perceived to be ageism in the health service further on into her treatment, but her surgeon personally advocated for her to have rehabilitation and she felt a strong sense of commitment to getting well:

Mr H started pushing for me to be able to go up to S for rehabilitation..but I was a pensioner wasn't I? ...and they weren't going to send a pensioner up there, they won't pay that much money for a pensioner! After all I should have gone home and died within 6 months, shouldn't I? (laughs) he really had to fight to get me up there but I went up there for 2 months...and they got me on my feet and walking. It was very very intensive... I was falling asleep trying to eat a meal because I was so tired...I didn't want to let

anybody down... I had got to do my best...[for] everybody, I didn't want to let anybody down. At the rehab centre they were calling me the super quad because I was a quad when I first went there and there was one chap in the gym and he called me 'his star'....I got encouragement from everybody.

For Dee, the fact that her GP did not take her initial presentation seriously could potentially have had fatal consequences. Again, we see how otherwise assertive adults can demonstrate deference to the medical profession:

I found this lump so I went to the GP and she examined me and told me that my breasts were granular, that was what she said. She said that everything was Ok. I didn't really have any insight into what you should be looking for...Anyway, I went away from the doctor thinking 'oh, oh' because you put your faith in them, don't you?

Again for Dee, it was a friend who encouraged her to seek further medical advice:

as time went on my breast seemed to get larger and the lump got bigger and I just thought it was me and I kept thinking 'no, not really', I didn't really want to know. It was about 4 or 5 months down the line and I took my bra off and I noticed that it was making an indentation on my breast and I thought 'I really ought to go back'. I was out with the girls actually on one night and I was saying about what had happened and one of the girls said 'you must go back' and I went back the following day and she sent me to the clinic

Dee did not seem to think that, when she did present herself for further medical investigation, anything would be found amiss; for her the hospital visit was on a day like any other day – she had offered to provide childcare for her son's friend and she knew that the children were waiting for her at home. She expresses a sense of denial, of not wanting to know the eventual diagnosis:

they did a mammogram and then I had to wait in the waiting room and still I didn't think anything was wrong. I had left my son and his friends at home and I was going to take them [swimming] later so no alarm bells rang. They did a biopsy while I was there... and still nothing registered with me, I thought it was all perfectly normal and he put the X-ray up on a screen thing and he said 'how long have you had this lump?' and I burst into tears then and I think that was because suddenly the penny had dropped... I can't remember how long it was after I had actually had the biopsy that they actually told me. I know I had to go back to the same place and they said it was cancerous and that I needed to see a specialist. The sort of things that

happened then are a little bit hazy because I think that you go into a mode where you don't want to know, I think you go into denial.

Dee's faith in her original GP was understandably shaken, to the extent that she did not see her again...in a professional capacity. But the significance of the GP's misdiagnosis and the potentially fatal consequences it could have had for Dee never left her. Nevertheless, Dee's anger with the GP is tempered by the very fact that she is able to look back and think these things from a position of survivorship, which seems to override all expressions of negativity: "but still, I am alive..."

Dean was also 'fobbed off' when he first sought help for his violent headaches and vomiting – "there is nothing wrong, you are just having lots of headaches, keep taking your pain relief"- but, following his presentation at NHS Direct, "within a week I got an appointment and I went and then on New Year's Eve I was told that I had got this brain tumour... I have now had the brain tumour for 4 years, 2003 going into 2004, this year I will have had it for 5 years..."

Dean was faced with an important decision for which he felt ill-prepared. He was frightened by the responsibility of being told that he had to make the decision about what course the treatment should take. He was told:

'...what we could do is we could leave it and see how you go or we could take a biopsy and see the sort of grade of cancer we are dealing with and then obviously we can then see where to go...' He told me that the decision was entirely up to me ...Well, I thought it was dreadful, because he said that there was a massive risk in brain surgery and obviously because I was, I think what frightened me the most was when I was agreeing to all this all these factors came into it...

Dean was scared by the sight of others in the 'cancer community', which indicates the difficulties which can ensue from patients receiving treatment en masse:

I think what really caught me off my guard ... [was] when you are in the waiting room and there are people waiting to have their treatment, there was a guy opposite and he was absolutely riddled, he looked like he was on his last legs. Someone like me, I think, 'oh my god, am I going to get like that?'

Dean expresses very clearly the fear he experienced at the time of his diagnosis and treatment, as described by Craib (2003) (see Chapter One):

where my tumour is they can't take it all away because obviously there is a massive risk involved and it would lead me to be paralysed...So I asked what was going to happen, I went into the hospital I was very frightened, more frightened than ever I think

Dean points out his feeling about his tumour, which was impossible to remove completely, and the fact that it felt 'alien' within his body: 'you know if somebody says to you they have cancer, they are thinking 'let me get rid of it, let me get rid, I just want it out...'

Beth seemed to have nothing but positive experiences in her engagement with the medical profession and seemed to 'sail through' her treatment with no problems. She particularly appreciated the consultant's friendly communication style. This relationship seems to have been good preparation for her experience when her husband was later diagnosed with terminal cancer and was under the same consultant:

I had treatment every day for three weeks, Monday to Friday. I used to go into work every day...and I just finished there at lunchtime and drive up the road to the hospital for my treatment. I didn't have any bad effects from it and he was absolutely great...I just saw Dr G all the time and I did see him privately... I was under him for 10 years...and then he decided I didn't need to go any more. But then I did see him again because of course I saw him with D [late husband]...D got cancer 3 about three years after me.. He [Dr G] was so natural and friendly, as if he was talking to a friend really. There was no aloofness ... he was just a nice sort of family man...because we chatted so, I could have asked him anything but he was just honest, I suppose...

Margaret also seems to have had a positive straightforward experience of engagement with the medical profession – her account is characterised by acceptance and no sense of alarmism:

In July 2006 I wasn't feeling well and I was thinking what could be the matter with me? I thought well, I haven't had a mammogram for a long time, maybe something is happening with the breasts. ..I made an appointment for Dr C which was in about 10 days' time but I was thinking 'oh, it is not

urgent, I will just get checked over'. In the meantime between making the appointment and getting the appointment I had found a lump so I was then a bit suspicious. So I went along to GP and I didn't say anything about the lump I just said to him I am not feeling well, I haven't had a mammogram recently I wonder if I could go and have a mammogram and he said yes, I will refer you and you will get an appointment in 2 weeks which I did...so I went and had my mammogram on my own and I had a scan as well, and I said was it cancer and she said yes...

Thus the respondents negotiated the first part of their journey, engagement with the medical profession and the initial identification of themselves as a 'person with cancer', which required some form of treatment. The diagnosis was met by some with shock, whereas for others it was confirmation of a growing fear, either in themselves or amongst friends or family members, that something was wrong. Many of the narratives are characterised by deference to the authority of the medical professional who did, or more often initially, did not, confirm the individual's fears. Thus it was often necessary for individuals to present themselves a number of times before their diagnosis was confirmed. The communication skills of the professionals involved in the breaking of bad news were commented upon and in a number of cases found wanting, but this did not seem to affect the individual patient's ability to put their faith and trust in them.

Relationship with Self

Another theme that emerged from my interviews was the idea of cancer requiring respondents to manage a new identity as a 'person with cancer.' A number of respondents spoke of their feelings about the changes which cancer and its treatment had wrought in their bodies in a physical sense, and the effect that this had had on their view of themselves, their body image and self-esteem (See Chapter One, Biographical Disruption and Identity; also Charmaz, 1983; Charmaz, 1995; Charmaz, 2002)). Awareness of body image tended to be more the case for the younger women, but not exclusively so, and this represents a challenge to health and social care policies and practice which may be predicated on gender and age assumptions about the relative importance of physical and psychosocial care. Some

respondents spoke of the effect that cancer and its treatment had on their ability to think and act, and the different ways they found to overcome this, and to find new (or adapted) roles which would give them a sense of self-worth and fulfilment. The theme of faith and spirituality was also significant in many accounts, as respondents found support in pre-existing patterns of belief or discovered new ways of channelling their energies and anxieties through meditation and reflection.

Physical and Emotional Changes- Being a Patient

Teresa, diagnosed with breast cancer, spoke graphically of her decision to undergo a double mastectomy because she felt that her body had betrayed her:

it didn't take me long actually to decide that I wanted a full mastectomy because I actually felt betrayed by my breast and I wanted to get rid of it because I didn't trust it really...At the time, the fact that my body would be mutilated, because it is, that is a strong word to use but you are having something amputated, let's face it, and to me it mattered more that I was living

Despite not regretting her decision to prize her life above her body image, the cost of this decision in terms of its effects on Teresa's self-esteem has been immense.

it is not something I am happy with because it has really affected my self-esteem...I mean, I think having lost a breast makes you feel less feminine...I, at 43, lost a part of my body which you never stop feeling attractive, it has stayed with me...I don't regret the decision [to have my breasts removed] but I wish I had both my breasts ...

Teresa spoke about how many references there seem to be to cancer and its effects in daily 'normal' life and how negative thoughts about oneself can be triggered, for example, by reading a novel:

I look at myself in the mirror and I have just read a book ...and he had got an older man with a young mother and she had breast cancer and I thought 'this is not what I want to read'...and that was awful really because it just reinforced how I felt about myself. She had him take a picture of her breasts before she had the operation and sometimes I think 'Oh, maybe I should have done something like that', you don't know, because you forget what you looked like and however much reassurance you are given it is a scar

Teresa talks about how her missing breast affects her day-to-day decisions, for example, what clothes she chooses to wear:

I don't grieve and nurture it, I mean, I have not got big breasts anyway, but it would be nice to be able to feel less self-conscious even to the extent of wearing a nice outfit, sometimes you think, 'oh, that is really noticeable'...I can't wear anything low cut because I have a big scar here, not that I would wear anything low cut, but I am very very conscious...You have to think about what swimming costumes you get and it is not always easy

On balance, though, Teresa feels that she had to choose between her breast and her life and that, despite her reservations, she made the right (only?) choice "There are times when I feel sad about it, well, I suppose it is just there, it is just there and it does have an enormous impact on your life. At 43 to lose something like that, but at least I'm alive, well, not at least, I am alive"

When Jo underwent a mastectomy aged 49, she made the decision not to undergo reconstruction, much to the consternation of the medical team who were responsible for her after-care:

When I decided not to have reconstruction and not to wear a prosthesis, I was told, by a nurse, that I should because it would make other people feel uncomfortable. And for at least eight months, every time I went for follow-up checks, my consultant would say 'when you decide on your reconstruction I know a marvellous surgeon....'

Jo found that the place of ritual and memorial was helpful in 'letting go' of her previous identity and becoming a 'one-breasted woman':

Before I had surgery, I had some photographs taken of my breasts, for posterity, as part of my counselling process and coming to terms with the inevitable. It was a painful and emotional process, but very cathartic and one I would not have missed. I look at them now and then...Another therapeutic moment, after I had decided to be a one-breasted woman for the rest of my life, was looking through my wardrobe and giving some of my favourite clothes to friends; first trying them on, mourning my lost breast and new shape and giving them away with a good heart.

Mo, a relatively young female respondent with breast cancer, recognized that there is something particularly emotive about the disease connected to society's view of

women, femininity and body image: "...breast cancer is very emotional, it is women, it is breasts and it is, you know, part of a woman's identity and also I was diagnosed about 4 months after Kylie Minogue and so, yes, I can understand that...."

Hair loss or changes in its condition were also mentioned by a number of respondents as of particular significance. For Faye, her hair loss had a profound effect on her body image and sense of self – her hair had been a source of pride to her and she was very distressed when she began to lose it. However, she made the decision to have it cut off and to wear wigs – which immediately attracted positive attention from both male and female friends and acquaintances, and those who did not know her well or who had no knowledge of her cancer diagnosis complemented her on her new hairstyle, which they assumed she had chosen. This helped Faith in her recovery, as she realized that she did not always have to be identified as a cancer patient, but as an independent woman who could still make choices about how she presented herself.

...losing my hair I have to say was the hardest thing about the whole experience. I had really long hair, down to here, I have always had long hair all my life and so that was really really hard. Because it is so visible as well...

S Did you wear a wig?

F I did, yes, it was interesting really because it was fantastic, it was longer than my normal hair and it was shiny (laughs) you never have a bad hair day, do you?!... actually this wig got the most amazing reactions and in fact one of the mums said 'wow' Faith, your hair is gorgeous' and then someone was like 'sshh' and she suddenly realized that it was a wig. She came up afterwards and said 'I am really sorry I shouted out but you looked so gorgeous, you looked like a supermodel' and I said 'actually S, that was the perfect reaction'.

I am quite a confident person but actually the first time I put that wig on and walked out I was sure everyone would be looking at me and thinking 'oh my goodness, she is wearing a wig, what does she look like?' 'I stood at the door and I thought, I haven't done anything wrong. I have had a disease which has taken away my hair, I have done nothing wrong and I am going to hold my head up high' and I took a deep breath and I walked out and actually the fact

that she reacted like that was really good because she had forgotten that I had lost my hair...

Perhaps the effect was not so strong for Faye because she was already possessed of a great deal of self-confidence and was careful to recognise and manage the feelings of others, using humour to ease their embarrassment and anxiety.

...I think I was quite strong anyway. I did actually try to turn the whole thing into a very positive experience and I did try to make it easy for people around me because I joked a lot and I was sort of saying 'oh, I never have a bad hair day' and so I did make a joke about a lot of things, including the fact that my boobs would never be saggy. I sort of tried to make it easy for others around me.

States of Mind- Influences from the Past

Mo realised that how she reacted to her diagnosis was influenced by her character and what she had learned about cancer in the past:

I think there are three things in terms of how I reacted, the first thing is that myself, I kept thinking, there was an advert I think probably when I was in my early 20s because we hadn't got a telly at home so it must have been after I left home, and I assume it was for cancer research or something like that and it was 3 girls playing together and the message was that 1 in 3 people had cancer and one dies and I kept thinking 'I wonder who the other two are, I am one and who are the other two?' and whenever I was in a group of people I would always think 'I am here and how many other people..?'... I work with statistics so that interests me...

A number of respondents had experienced the diagnosis and subsequent (often poorly-managed) death of a family member from cancer, and this often seems to have increased their fear and anxiety about their own diagnosis. Kate's diagnosis happened about the same time as her father was dying from cancer and this seemed to divert her attention away from her own problems to his. For many, though, the memory of 'cancer in the family' was something that seemed to have been passed down through generations and had achieved almost mythological status. For example, Dean's brother had died of a brain tumour at the age of seven, but this was not spoken about and when Dean tried to pursue the matter of genetic links to his

own cancer he seemed to 'draw a blank'. Sometimes it was a topic that was shrouded in silence and fear and kept as a family secret that was only reawakened when the respondent disclosed her own diagnosis, for example, Brenda could not initially understand what she perceived to be her mother's 'over-reaction' to Barbara's eminently treatable ovarian cancer, until her mother disclosed that her own sister (Brenda's aunt) had died from the same type of cancer a number of years previously.

Fiona's attitude to cancer was influenced by the fact that it had been ever-present in her family and she was almost waiting for her own diagnosis and relieved that it was a type that was not likely to result in untimely death. However, Fiona had also experienced the diagnosis and death of her youngest daughter of cancer when she was in her early twenties and she describes how the behaviour of her daughter when she [daughter] had had cancer influenced her own desire to 'live' for her, to carry out the fundraising activities she had instigated:

Well, I felt that I had still got such a lot and [daughter] had raised such a lot for leukaemia research during her two years and I thought 'I have got to carry on doing things that she would have been doing to make it a worthwhile life...it was carrying on for [her], doing what she would have been doing had she been here, sort of thing. She couldn't do anything for charity now and so it was up to me to do something...

Changes in Lifestyle – Managing the Present

Following their original diagnosis, a number of respondents undertook research into their particular type of cancer and adopted a pro-active self-help stance which sometimes involved quite radical lifestyle changes for themselves and their families. This can be seen as an attempt to try to reclaim control of their health from the management of the medical profession.

Faye, for example, undertook lengthy research into the illness and went beyond mainstream medical recommendations, exploring the worlds of complementary medicine and possible environmental cause and effects, recognizing particularly the risk her illness might pose to her daughter:

That year when I had all of my treatment, I spent a whole year just researching, looking stuff up on the internet, reading books... I really needed to know everything about it. We changed our whole lifestyle, we ate organic, I have given up dairy, we have soya milk, we don't have anything with chemicals in the house, our shampoo, our conditioners, everyone, the whole family...Particularly for my children and [husband], I wanted to make sure that they didn't get anything...we are all chemical free and we are all organic and it was all sort of oestrogen things because I was really worried about L [daughter] because I didn't want her to get it...

Faye speaks of different attitudes to her lifestyle choices, both within the family and from the medical team:

I am a sceptic and [husband] knows that I am a sceptic so that's why he's not drinking dairy because he said 'if you tell me to do it, then I know you have researched it in such depth that you really believe it and we should do it'. I am someone who 'pooh poohs' everything, I have to have the facts, but I really honestly read so much...I actually thought it was logical and I have read lots of things since then in various magazines and articles about it. I think at the time the hospital said 'if you want to do this then that is fine' but they were sort of a bit 'it's up to you' type thing. They certainly weren't encouraging it but they weren't discouraging it, they were saying 'if you find it helpful then do it.

Susie also made radical changes to her diet, following her diagnosis and reading up on research by a local scientist who advocated a non-dairy diet for people who were living with cancer: "She and her husband researched on Eastern women and they found that when they didn't adopt a Western diet, the incidence of breast cancer was very low...I watched the tumour disappear...I [stayed on the diet]..for a very long time..."

David, who, as a teacher of young people with challenging behaviour, had always relied on his mind and ability to 'think on his feet', found an unusual way to manage the changes cancer and its treatment had wrought in his body and mind:

I couldn't concentrate on anything, I couldn't read a book, but one of the places I could walk to was a local bookies and I am not a betting person...Radio 4 in the morning gives the names of 2 horses...and I had to have it written down because I couldn't remember the names of the horses, I could either remember the names and I couldn't remember the times, or the other way round. I could remember 2 or 3 bits of information so I put it on a bit of paper that would say the name of the horse and the time of the race. I kept a little book and again it was just a bit of fun... it gave me something to aim for, halfway down, the walk, it gave me a purpose, it gave me a little bit

of a buzz and I think I came out evens over 13 months... it gave me something to wake up to in the afternoon.

David was able to adapt his existing skills to take on similar but different challenges in the workplace, but this time he was in charge of his time and commitment and taking responsibility for his own health and wellbeing:

Again, I got involved with a school and again you are talking about what builds you up, a school said to me 'would you like to do a little project management for us?' because they knew me and they knew my past.. [I said]...to them 'I will come and do it, but it will have to be on the days when I can do it...which is a bit like managing your own business...so I enjoyed doing work, but in my own time and in my own way and the good thing for them was they didn't have the time to put quality into it, so I could do that because I only had one thing to think about....Wasn't it nice that somebody gave me a chance and a step up?... the other one was a theatre company and I had been on their steering group for a while up in Leeds and they said 'oh, would you do a little bit of work for us?' So suddenly I am back into a work environment, but with choices, with freedom and a nice notion of the opportunity to do different things.

David also took on a new challenge, within the world of cancer itself, but was careful that, by incorporating his new 'cancer' identity into his on-going life, he did not become subsumed by it:

So when you look at survivorship and people coping and managing, then of course there was another strand to that, as you know, because I was getting involved in a local cancer support group, so here with three quite different worlds....Not focussing on cancer, but drawing on some of my previous experiences, drawing on education and eventually it became a sort of mantra of mine to move between different worlds...and you transfer and adapt accordingly....

Finding Meaning – the Place of Spirituality

A number of respondents spoke about the relevance of spirituality and religion in terms of their personal support mechanisms. For David, individual spirituality, not formalized religion, would seem to define his experience and he feels that cancer has brought him in touch with the fundamentals of existence and what really matters in life. Although he sees his experience as a personal matter, during his treatment phase, he preferred to 'keep his options open'!

I have no real belief, I do not believe in some God in some place but if anybody was willing to pray for me and I had Muslim prayers, I had Christian prayers, I had people come to the house and I was very happy to have that. There is a kind of hedging my bets...

I have a deep spirituality, so when somebody comes along and takes me in their hands then I am perfectly open, if they then want to sell me their religion I am more drawn to withdraw if you see what I mean. Do you know Maslow's hierarchy of need? You need food, and if you take away that I didn't have food, so my idea of cancer if you like is an inverted Maslow...actually cancer gave me a transcendence, so that faith and that spirituality, which is an element of that, became quite deep

For Dean, faith and spirituality did not play a big part in his life either before or during or after his diagnosis, but even he on occasion chanced to say a prayer, suggesting a motivation to believe in times of crisis: "I haven't really got a religion as such. I can honestly say that I did pray a couple of times, but I haven't got a strict faith and I didn't wonder why it was happening to me rather than the next person. I feel that things are there for a reason –"

Faye recognises that her Christian faith had been a big part of her life since childhood and that this remained a source of support and succour throughout her illness:

I became a Christian when I was 6 so I have been a Christian all my life virtually. Yes, I mean, I have to say that I think having a faith really helped me. Interestingly a lot of people sort of think that maybe you would be angry with God because he has done this to you.... I found it a support and I think that if I hadn't had my faith I would actually have struggled a lot more... and you know, bad things happen to good people. Just because you are a Christian and you believe in God does not mean that is a life insurance policy and you are not going to die. C (friend) died, you know, how do I explain that? And I do find that really hard but you know, a young lady with two young children... I am really glad that I am still here but I did actually get closer to God and the pastor said that often people get further away from God when the times are bad but actually for me, that was a time when I really needed him and I had to lean on him a lot more and ask him for more help....There is a passage [in the bible] that says 'the Lord will never test you beyond your capability'

Faye's faith was obviously very significant in every part of her life and so perhaps it was natural that she should apply it to her cancer condition, too – however, she also

spoke about faith and more specifically, prayer, as something that she had researched in connection with cancer:

There were a lot of things at the time that I really felt that God was speaking to me on and yes, I think it really sustained me and I am really grateful that I had a faith beforehand because I think that did help me. I did lots of research and one thing that came up was the prayer...They had complete strangers praying for a group of people with breast cancer and the people who were being prayed for did much better...

Fiona's faith supported her through her operation and treatment and gave her an attitude of selflessness:

I said 'beside the family who it will be a shock for, you feel sorry for yourself because you might not have achieved what you wanted to do but hopefully you might have discovered something that will help other people so something positive could come from it... if I survive the operation, it is the Lord's will that I should and he will have a reason for it, so whatever state I was in, I would trust in Him to look after me...

Fiona had a fortuitous meeting with a consultant who shared her Christian faith, and his openness about his faith was a source of comfort and reassurance to her, as he told her about his practice of praying with patients:

they then showed the scan to Mr H who wasn't always at the hospital because he went round the world lecturing he was world renowned and they called him the miracle worker...They told me that if had been in any other country, any other city, anywhere else at this time I couldn't have got the operation that he did for me. I was here at the right time to get him. He looked at the scan and he came to talk to me and he spent a whole hour with me, really talking it through. I told him I wanted him to be honest with me...and I told him that I was a believing Christian and he told me that he was. He said that he always prayed for the patient beforehand and he prayed for himself and for the staff, prayers were always said before any operation. He said, "I can't guarantee that you will survive the operation" and I said 'well, if I don't, lucky me, straight through to eternal life...!'

Lisa also speaks of her Christian faith and how it supported her – "I think that my faith really stood the test of time". Lisa actually went to stay with a family from her Church for a few days after she was diagnosed" and she also appreciated the disclosure of a Christian nurse who worked in the chemotherapy suite and who used to pray before she put the chemotherapy in "...and that made a huge difference."

Brenda's situation was complicated by the fact that she had experienced deafness and long-term mental health difficulties before she was diagnosed with cancer, and she compares the support she got from her Church (Catholic) before and after her diagnosis, relating it to her vulnerability and presenting herself as someone with a visible disability who needed and would accept help:

in the time I had been there nobody from Church had been through the door. I was very lonely which didn't help the depression...[but after her cancer diagnosis] they visited me with flowers and fruit and one thing and another ...when I was diagnosed with cancer that made an enormous difference. I was vulnerable, I had admitted that I was vulnerable, whereas with the deafness and the depression I hadn't admitted it. It was obvious because I had something physical...

Margaret's Christian faith was very important to her and had sustained her throughout her first husband's terminal illness:

"it was just through the prayers, I was on the prayer list and I was on the prayer list at three churches I think...I never questioned it... I did feel that there was a God I can lean on, can I say...when my first husband had cancer I just used to sit up and pray or read the Bible in the night, if I couldn't sleep it was just an automatic thing to do...it has helped me a lot..."

Margaret's attitude to death and life and cancer was in part influenced by her faith, but also her age and life stage:

I have never really worried about dying, I think it is more important to live well...[partly to do with my faith] although I think it might be because I have always been in nursing and in that line of work you face all different kinds of problems...and also when you grew up knowing that people died of illness...

Robert's religious practice had changed since his illness – he used to attend Catholic Church with his wife and family, although he himself was not Catholic, but disliked the emphasis on socializing, eschewing Catholicism for a more solitary, meditative practice of his spirituality:

I did enjoy going to the Catholic church but I am afraid with all these different things it is not for me...I started to look into the Anglican Church ...and I suppose I go about once a month and the vicar there.. I asked to see him at a time when it was all falling apart really, work and my home life and he was really nice and it was someone to check I with...I just had that one session with him but I would see him now and again...I go there really just

as meditation really in the early morning it is nice and quiet and it is not hymns or anything like that...it is more about my faith in humanity and the kind of specialness in being alive and that because the religion does connect throughout my life, I didn't always want to go to church but there has been a continuity in spite of that. It is just a little but extra that I think balances all the TV and commercialism and all that kind of stuff... I like for instance at home on my own I sit with a cup of coffee and gaze out of the window and I have a quiet time

For Jean, being diagnosed with cancer reawakened her interest in Buddhism, which enabled her to develop a meditative spirituality: "it is about acceptance of things as they are and of living in the moment...and realising that actually what I wanted to do was live how I lived..."

For Mo, spirituality was something that was mediated through other people, and it did not influence how she viewed her illness. Instead she had a biomedical view of health and illness:

...we at the time were going to Quakers...they were very supportive people and I had ever such a lot of support from them from cards initially and then visits all the way through. I suppose the question is really was that spirituality tested in the other way, you know what I mean, you can come to a spiritual awareness through adversity or you can lose it, but I didn't ... I think that again... because of my medical background...I was a physiotherapist in a previous existence, so you know about disease and the body changing and you know that it is not, you know, it is not pinpointed on one person because of the way they have been or the way they have reacted type of thing, or the fact they have sinned or whatever...it is flesh and it breaks down sometimes and it may well be because I had been drinking too much ten years before, you know, I don't see it as a spiritual thing..."

Beth's philosophy of life and death was influenced by her earlier experience of loss and this can be seen to have affected her attitude to her cancer:

There was something in the papers recently wasn't there about that person that wants to go [to Switzerland]...And I think 'just let her go', I think it is so awful and it's not a good life when you have got something like that...I have never been one that thinks you should hand on to life regardless, you know. I had twins that I lost when I was first married and people used to say to me, there was nothing wrong with them apparently other than the fact that they were very very tiny and of course it was years ago, nowadays they would have had a better chance, but I used to say 'oh no, if there is anything wrong with them I think it is best that they haven't survived..."

Having considered how the experience of cancer had affected their relationships with themselves, their sense of identity and coping and what helped and supported them through these initial stages, this next section will consider a related theme that emerged from the narratives, that of how the individuals in the study related to the world beyond themselves, to friends, family and in the workplace.

Relationships with Others

A third theme centred on the management of relationships with others, with family and friends, which were affected by the changing identity and relationship with themselves that respondents were simultaneously experiencing. For those with sole responsibility for others, for example, single parents, the threat to life invoked by the diagnosis of cancer brought the issue of dependency sharply into focus, and others were forced to reassess and re-evaluate previously taken-for-granted roles within family and friendship groups. Issues of work and employment were explored, including how the respondent was seen and treated when (if) they returned to the workplace following treatment. The role of self-help and formal support groups, both as a participant and as a facilitator, is also mentioned, although this is also explored further in the final section of this chapter, New Perspectives.

Negotiating Relationships – Ways of Being with Others

For Dean, it was the support of his partner that was the turning point of significance for him in terms of his attitude to his illness “I remember coming home that night and her asking ‘I don’t want to lose you’ and I remember saying ‘I am not ready to go, I am ready to fight’ so I think that was a crucial turning point...”

For Faye, it was really important to have the support of others, and again, to offer her support to others who may be more socially isolated, but not to force herself on them:

“He [husband] was there, yes, always, always. To be on your own when you hear news like that would be terrible, some people really wouldn’t have coped...I have since had lots of friends who have gone to the doctors with lumps and they have asked me whether I would go because I know the questions to ask...I have a friend at the moment who is single and I have said “if you want someone to go with you then I am happy to come” so I have left the ball in her court...It is her choice...”

Faye also spoke about how it felt when a friend with cancer did not survive:

Yes..[it] was actually really hard for me because we were really close. In a way we were good for each other because she had done it all before me, but she had gone through her treatment and she finished her treatment in November and I still hadn’t had my diagnosis yet, (10) but in the January when I got my diagnosis ...it came back in her liver and she passed away...She passed away in the November of my year of treatment as it were. We were close and she felt that she could talk to me in a way she couldn’t talk to other people so it was good that I could be there for her.

At one point it was suspected that Faye had secondary cancer in the liver, but this turned out to be a false alarm: she did not have secondaries, but she had to wait a couple of weeks before she received this news. Interestingly, however, that time of waiting was a valuable and salutary experience for her and one which taught her a lot about herself and her relationship with her friend, who was going through a similar experience:

so for 2 weeks I was really thinking that I was going to die, and it was interesting because I was avoiding C and we used to speak to each other day and I kept trying to sort of not answer the phone and eventually she got hold of me and said, ‘what’s the matter, I can’t get hold of you?’ and of course I burst into tears and explained to her what had happened and that I thought it had come back and that it was on my liver and, I know it sounds bizarre, but I never regret having that 2 weeks when I thought ‘that was it’ because it was really good for her...she was poorly but also she was trying to say ‘no, no’ it will be fine and I said C, you know, do you really think it will be fine? And she said ‘no, it sounds like you have got the same as me’ and what was good was that she could talk to me in a way that she could never have talked to anyone before

Faye experienced what could be termed ‘survivor guilt’, but also a new ‘lease of life’ to think that she was near death and to be given a reprieve – her second brush with mortality, thinking the cancer had returned in another site, gave her an insight into her method of coping if she really did have secondary cancer:

and then of course I felt really awful when I went back and they told me I had liver spots and I said ‘liver spots? Who cares what it is? I will have those, that will be better than metastases!’ but I felt terrible trying to tell her, I mean, she was obviously very happy for me, but it wasn’t....But it was good to have that 2 weeks, I think...I really thought my life was over and it is interesting because all through that first year when C was diagnosed and was having treatment I was aware of her all the time...This is before I was knew [about my diagnosis] and I just kept thinking ‘she has got young children’... and I found it really hard. Whereas when it happened to me, I sort of went into autopilot mode and thought ‘I have got to get through this, I have got to have my tumour out’ I hardly cried at all, I must have originally, but I was really quite composed, it was really very strange...

Faye’s own attitude to support and support groups around cancer seems to reflect more her interest in supporting individuals – and being supported- on a one-to-one basis rather than in a group context, and her desire to protect others from bad news. Faye realises that she had no real need for the environment of a support group because she was not socially isolated and also had a ready-made ‘community of sufferers’:

I had C and I had another friend from an old Church, an older lady, she showed me her scars, she was in her sixties... I had my friend Tanya who was sort of going through it at the same time as me, so I did feel that I had support from people that I knew. ... I felt I had enough support and then obviously I did do a lot of reading and looking up on the internet ... And I had people like the Macmillan nurse and the breast care nurse and so if I really didn’t feel that I had the answer that I wanted I really felt that they were there and I knew there were places and people I could ring...

However, Faye was also able to recognize that some people were more of a hindrance than a help and became more protective about how she spent her time, and who she spent it with:

Interestingly, when I was having my treatment the first time, I wanted to be surrounded by people who were supportive and positive and I had one particular friend who was an anti-natal friend, who I could not bear to be around. It was interesting, I would spend a day with her and I would feel so depressed because she is quite a depressive person anyway and even before this I used to find that I would have a coffee with her and I would come back and my head would be banging. Literally, you know, some people fill you up and some people drain you and she would really drain me...I really had to avoid her because I just thought ‘I cannot cope with you at the moment’...I

think you have to be selfish because sometimes you have to think about yourself.. Protection, isn't it?

One of the ways in which Faye sought to manage her new identity was by preserving aspects of her pre-cancer identity, that is, by also having a community of people with whom she mixed who had no knowledge that she had cancer, although sometimes this would be at great cost to her personal comfort:

...[there are also] acquaintances...people you meet at the swimming pool and I thought 'you know what, I am not going to tell anyone there' and it was the worst decision I ever made because you are sitting beside a hot pool and it was the last place you want to be wearing a wig and you just want to rip it off and there were so many times when I just thought 'I need to get this off' but you know what, I just wanted to have somewhere I said 'oh, isn't it good weather today' where someone didn't actually talk about cancer...Because you do need that because sometimes you just think 'you know what, I am so fed up about talking about this' and I am more than just someone who has got cancer. I am actually a normal person.

Faye can be seen to be acting as a bridge between the two communities, the ones with cancer and the ones without:

Interestingly one of the mums lost her mum to breast cancer and she came to talk to me when we were sitting at a competition, everyone knew that her sister had died and everyone was giving her a wide berth and I said 'are you alright, J?' and she said 'yes, I am fine'. She obviously didn't want to talk about it but the next day she came to sit with me and she talked all day about her sister and her mum and I just listened and listened...I think she just actually, finally wanted to, it was a bit like finally breaking the bond of silence... She...said it was really helpful, so people do remember that I did have it and they come up and talk to me about it and then if I did want to talk about it I could do.

Faye spoke of the importance of retaining a non-cancer identity, an identity apart from the cancer, in her relationships with others, and particularly the difficulty of forming new relationships:

Yes, my really close friends...are the ones that you surround yourself with at the time...because they actually do talk to you about other things other than cancer because you have got that history there and you can have a laugh with them and have a really good time without constantly being reminded about it. Other people just begin to see you as the person that has got cancer so that is harder... So I think it is quite hard to make new friendships

because you don't have any history, all you have is this disease to talk about whereas the ones where you have history you have other things in your life...

Faye tells of how cancer takes over one's whole life, obscuring the person underneath and taking over the whole family's life too:

That was quite hard actually because for at least a year afterwards you don't have a huge amount to say because what you have done for a whole year, you haven't gone on holiday, we had to cancel our skiing holiday and it was our fifteenth wedding anniversary and that got cancelled, we were going to go to Florida with the kids and that got cancelled so it wasn't like you could say to anyone 'what did you do last year?'...It was like, 'well, actually, we did nothing last year because I spent the whole year in hospital' because it literally is a year with the treatment and chemo and radiotherapy.

Fiona also speaks of the importance of having a few good friends, and the difficulties of 'fair-weather' friends, who do not see beyond the immediate signs of 'disability':

Well, a very small circle of friends that have been very very good. Other people, you know, they are kind but they don't understand and they don't want to understand. They say 'oh, you are looking well today, I am glad you are alright' as they walk past you...they don't want to know...if you try to tell them they say 'I know, I know' and they come up with their own situation and it ends up with you listening to them, to comfort them...people look at me and they say 'well, your hands are deformed, it is obviously arthritis and at your age people are a bit iffy on their feet...so many of my problems are hidden...It was the shock of my life to realize that my bladder and bowels were affected.

Many narratives are characterised by a realisation of the need for the patient to be independent - Kate realised that she would have to be self-sufficient, even though she had a partner:

When I had the, obviously my first husband T drove me to the hospital and brought me back after the hysterectomy things like that but he found it very difficult to talk about anything, so I just pulled myself together and thought 'I need to get on with this'. ...When I went to Bristol[Cancer Help Centre] I actually had a female friend that came down with me because I had had the hysterectomy but I was still struggling, I couldn't carry bags or anything like that...It was just for the day...I ended up going for a week and that was

after the first lot of chemotherapy... But I went on my own then, and when I was there for the week everyone else was there with their partners...I was the only one on my own... but [first husband] just didn't want to go...[first husband] did support me because he didn't leave me, you know what I mean, that was his way of supporting me. He supported me in the only way he knew how.

David also described what he termed the 'brutality' of cancer, and how it can divide people, of how this was a lesson he had to learn, for which he had had no preparation:

the brutality of the cancer, you learn afterwards that people react because of their experiences with cancer, but nobody prepares you for that. So you have a situation where you weren't sure that people were friends and they become true friends, and then some people who you thought were friends disappear off.

David speaks of the need during his cancer treatment to develop coping mechanisms in relating to others in order to manage his fluctuating energy levels, but he was also made aware of the need to recognize the importance of others and particularly the concerns of those close to him that he was withdrawing into his own world and in danger of isolating himself from the support of friends and family:

I didn't close the doors, but I chose the days when I closed the doors and then the days when I chose to come out... on other days, I would just close the door and say, just let me sleep. But there was an issue where my wife shook me up a bit because I would have gone inward and she could see me closing and she shouted at me and said 'get out, D, it is bloody cancer, but get out' and part of that was driven by her fear. Her fear was that her father had had depression and had closed off and he took years to recover from that and she could see me going in and the depression drawing in...She told me I just couldn't sit around and I got angry but actually, you have to have that...

David is able to objectify his own experience and realise why other people may have reacted as they did to him as a 'person with cancer', generalising from his own experience and recommending that cancer patients should be given more warning about how other people may react to them :

we don't do enough with cancer patients to say that people react from their own experiences whereas what we do is take it highly personally...you see it in their eyes, their eyes change because they have realized they have started a

conversation about somebody they knew who had cancer and then they realize they can't go to the next bit because it is the fact that the person died. But actually I love those people because they at least try.

Faye described how her family were affected by her cancer and how she feels that the experience of cancer is worse for others than for the person with the diagnosis:

I have to say that my mum and my husband were much more affected by the whole thing than I was...Because they can't do anything about it. They are watching someone that they love go through this process whereas I actually had to get on with it and do it. They felt helpless although they weren't, I think they felt they were....He [husband] came with me all the time, every appointment, every chemo... we are really close, we have been together for 22 years now, we are really close...

Faye recognised that her relationship with her husband had changed as a result of her experience of cancer, in that he had had to perform intimate personal care tasks which were not previously part of their relationship, but she felt that it had brought them closer together:

He was brilliant, he did so many things that husbands shouldn't have to do. He shaved my head when I had a tiny bit of hair left...I think in some ways it has probably brought us closer together.

Faye spoke also of the importance to her of the support of her mother, not only because of the closeness of their relationship but also because of her mother's medical knowledge:

My mum and I have really always been very close actually...she has always been there when I have been in hospital which I am very glad of because she has got medical knowledge and sometimes she is going 'this has not improved properly'. She is very protective and I think 'if something is going to go wrong, my mum is going to pick it up and she is going to make sure that the nurses get it right.

For Dee, the composition of her family changed, at least initially: "I think the main thing was that because my son was fairly young, he was eleven, my attitude was 'I have got to stay alive' and all I wanted J (partner) to do was to look after him. He actually moved in with us for a while..." Friends and relatives adopted different roles

as a result of Dee's illness and she was also made aware of the benefits of living in a supportive community:

...My friends were all very supportive, my female friends, and my sister and brother in law, they were just unbelievable, they were fantastic, really good. Neighbours, they were all good...I think because I live on a close, it is quite a close-knit community...

Later in her interview, Dee spoke poignantly of her fear of embarking on a new relationship of intimacy following her mastectomy: ‘

Well, because I have split up with J and if I go into a new relationship now I am terrified that somebody will turn around and say ‘well, I can't deal with this because you haven't had reconstruction...That is what worries me, so I just carry on as I am...

For Teresa, her diagnosis was a time when friendships were tested, and sometimes found wanting: “It was during that period that I found out who my true friends were...One friend in particular didn't see me for about 6 months...I never talked about it with them...they couldn't cope with it...but you know, our friendship did endure that and when my friend was ill I felt I could support her.”

Teresa found that some members of her family might be appropriate to undertake practical tasks but that they might deplete her mental energy:

You notice I haven't mentioned the family support while I was there at all...The way they behaved wasn't helpful to me...I think families can really complicate things because there are expectations about your role in the family and what you do...I have a very complex family and my mother did come over to help when I was going through the chemotherapy but she sat in my bedroom and started to talk about things like embryonic research into Parkinson's and then she started talking about the baby she lost before I was born and things like that you see...so it got to the stage where I had to say to [husband] ‘I don't want her here anymore’...She was fine on the cleaning up and the making cups of tea...but she just depleted my mental energy...

The Role of Formal Support – Identifying with Others

For Bill and others speaking about re-building their lives after cancer, the more formal support offered by a facilitated group for those with a similar diagnosis was experienced as invaluable. For many respondents, membership of a support group was not something that they had ever before considered in life, but despite an initial reluctance, they found the groups helpful and supportive:

The saving grace was that the few short weeks between the March and the April I [Bill] had been operated on, been discharged and been put in touch with the Oesophageal Patients' Association and I had actually attended one of their meetings...the Oesophageal Patients' Association and the hospital have a working relationship in that there is back up for everybody...

Similarly, for Robert:

...and one of the things I did was, I enrolled through my GP's suggestion on this Expert Patient Course...I thought it was very good... I think it addressed things at the right level and it is about coping or managing and being able to be in charge, I suppose. It is about living day to day as positively as possible and not becoming a victim ...It was almost like 'here we are, this is our programme, listen to us, we will take you through it and it will have some benefit...they were very committed and I liked and respected them and they were using their own experiences, but I felt that people had a need to talk a bit like how I am talking now to be honest...

Dean had very good long-term relationship with GP and he suggested that he attend a Cancer Patients Support Group, to provide support for Dean that would be more appropriate to him than one-to-one counselling:

my GP at the time...he was a fantastic GP I was going through a stage when I really didn't know which road I was taking .. I was really having dodgy days and I was going back and forth to the doctors with different things, I felt as though I didn't know which way I was turning and he said to me on this particular morning 'do you need any help?' and I said 'I can't sit with a total stranger and pour my heart out to somebody, I can't do it' and he said to me 'look, I know of a group. Take this number and give her a ring' and I thought 'oh, I don't know' It took me 3 days to ring. I did ring and ...then I was on the phone for 3 and a half hours'

The level of support provided by the group leader would not have been appropriate or welcomed by everyone, but it was appreciated by Dean.

I went to the group and I was very very nervous the first time. S [wife] went with me and I don't know, it totally changed my perspective. ...I still go...There is usually a speaker and...F's [group co-ordinator] knowledge...I just feel she is one in a million and you can't say that about many people. She would absolutely give you her right arm if you are not well. I remember her sending me a card when I was in hospital and she rang the ward many times

This level of support would not be appropriate or welcomed by everyone, but it was the right thing for Dean at the right time.

Informing and Involving Others – Telling the Children

For Faye, the children were very much a part of the whole experience:

“I have to say we had a lot of help from the hospital, they gave us a booklet on how to tell your children and that was really helpful...

S- And at what stage did you tell them?

F well, they twigged that something was up

...gets upset

S obviously you said that they were aware that people were upset and there were flowers everywhere, this was right at the beginning...

F [daughter] was only 4 and we basically just told her as much as wanted her to know, we told her that mummy had something bad in her boob and that mummy would have to have an operation and some medicine to make her better. We didn't tell her all in one go, we sort of told her as we were going along.

Faye recognised the differential in ages of her children and therefore she and her partner decided to involve them and to break the news to them in different ways, according to their ability to concentrate and to understand.

So we told [daughter], I mean [son] was obviously older, he was 8 and we used the word cancer with him because we thought he might hear it... We just said to him 'if you ever want to ask any questions just come and ask mummy or daddy'...so in the end he was very good at coming to ask us and he wanted to know all the gory details about the blood coming out when I had my drains, he was very inquisitive after that and about me losing my hair...I think in the end we just answered the questions as they arose...

As a single parent who had gone to the clinic thinking it was just a routine visit and not expecting to be told that she had breast cancer, Dee had to think quickly about

how to behave when she returned home to her 11 year old son who had been playing at home with his friend.

I honestly didn't think that they were going to say 'you have got breast cancer' but when I got back I was quite upset and I said 'well, I'm sorry but you can't go swimming' because how do you explain to an 11 year old that you have had a biopsy, especially on your breast, I mean, how embarrassing. I can't remember then what we did. I think we all just stayed at home because I remember that [son's] friends were there because their mum was working and it was during the school holidays, but anyway, I think I told my partner.

Robert initially did not tell his children about his illness, he tried to carry on 'as normal' – for many years, he did not acknowledge his cancer to be a life-threatening illness - but eventually he felt he had no choice but to disclose it, which seems to have come as a relief:

Yes, my diagnosis was in 2003 and I went back in November 2004 so things within the team started really to deteriorate really from summer 2005. I, I can't remember what time it was, D (wife) and I decided that we needed to tell the children and we did that I think in 2005, the summer, and that went, well you know, it was important to do and they took it on board. The main thing is, I think, in terms of selfishness, it was a relief, because it meant that I could tell other people and I hadn't previously and also I wanted to show the kids that it wasn't making a lot of difference to my life and that I was carrying on as normal...

Dean was quite clear that he did not want to tell his children about his diagnosis, or rather, that he could not, although he was also aware of societal expectations about the importance of involving children in all matters of life... and death:

I didn't tell them, I couldn't really bring myself to tell them, I don't know why. So obviously S (wife) told them. My eldest son, I think he knew a little bit more, but my younger son, I don't think he was clued up at all... I try and keep as much back as I can. I know some people would think I should tell them... I think at the time there had been a couple of deaths in the family and people would say 'oh, you know, you should have let them go to the funeral' but my belief is that it is not for the children to go to a funeral, I don't know why, I just feel it is not the place for them... I try and protect them as best I can...

For Mo, there were also complications surrounding telling her children – she had two children in their early teens at the time of her diagnosis, who she perceived were at a difficult stage in their own lives, but she judged correctly that a factual truth-telling approach would be best:

S is the younger one and to put it into context he couldn't even bring himself to think about where the cancer was because he was at that really awkward age...so for him it was nearly impossible to even think about it, he didn't want to. N was better, but we sat them down, on the day we got the diagnosis, we sat them down and we said 'we just want to say that mum has got breast cancer and is going to have an operation and treatment and we wanted you to know' and they both sort of sat and looked at us and then one of them, I can't remember which one it was, said, 'are you going to die?' ...and I said 'as far as I am concerned, no, this is a very small operation to get rid of it and hopefully the treatment will keep it at bay and we can get on', and that was all he wanted to know.

Work and Occupation – Being Outside

The sympathy and support that accrued to respondents after treatment did not always continue for long afterwards...although the respondent felt different and that life had changed irrevocably, that view does not always seem to have been shared by those around them, even by those who had themselves experienced cancer.

For Teresa, for example, was given no acknowledgment of her changed status when she returned to work and felt she was expected to behave as though nothing had happened to her:

Treatment finished in January and I was back at work in February and not even on a phased return....and the first day I was back the person that did part of my work came into my office with a load of files, plonked them down on my desk and said 'thank goodness you're back, over to you' ...

Although in a sense she appreciated not being given 'special treatment', she felt that things were definitely not the same as they had been for her and that some acknowledgement of what she had been through would have been helpful:

I had gone through such an enormous experience, it all happened in a whirlwind and you don't have any time to get used to it and then you are pushed back, or you push yourself back into normal life, thinking that that is the solution, to get on with it and it is partly the solution but at the same time you are dragging along this whole burden which nobody understands but yourself because they can't because they are not you and you try and rationalise it in your head and you think, 'right, I have got to be normal and carry on' but I don't really feel like it and I would kind of like someone to be a bit kinder to me

Despite the difficulties in her workplace, Teresa realized the importance of not making too many changes too quickly. With the reality of the need to have an income ever-present, there was the sense of 'better the devil you know', or conversely, the devil who knows you. Thus Teresa did not feel that leaving her post was an option:

I carried on working in that environment for another couple of years because it wasn't the right time to look for another job because I had to settle back into it and I wanted a period of stability, although that wasn't a nice environment to work in, but I had also got reconstruction operations. The whole thing you see went on for two years [but I would ask does it ever really end?] because you had to wait until the operation scars had healed and then you went through the complication of reconstructive surgery which meant 2 more operations, so I couldn't afford really to have too much change in my life . We needed the money as well, G (husband) works in the steel industry ... which was not stable which was all the more reason for me not to give up work really, not that G put any pressure on me but I put pressure on myself..”

Kate reports feeling abandoned by the medical profession and experiencing a feeling of uncertainty and vulnerability after the rollercoaster of treatment and hospital visits had come to what seemed to be an abrupt end:

but I found that one of the hardest things and most challenging things because suddenly my life is just thrown up in the air and my life for a whole year was just hospitals, home, hospitals, back to the hospital for treatment you know. My whole life for a year revolved around that and then all of a sudden my treatment stops.

It is quite interesting because I will always remember this ... a friend of mine said to me 'I bet you are really pleased that the treatment has stopped aren't you? And do you know what I even surprised myself because I had to stop and I paused and she looked at me and I said 'I don't know what to say' I suppose in some way I was relieved that I didn't have to go to any more chemotherapy treatments but also it was like there was a little voice in my

head going ‘well, has it worked?’ and there was no one I could talk to from that point, there were no nurses, ok, I kept seeing Dr C afterwards, on a fairly regular basis, but the time gets bigger between appointments and it is the support after that I find...you think, what am I going to do?

Kate experienced a problem with trying to ‘manage’ at work without revealing her cancer identity and the detrimental effect this had on her health:

I actually ...did a bit of catering because I had done some of that before. The problem I found was that because I didn’t really want to let the staff know what the situation was, apart from the manager who had to know because I didn’t want, you know, I didn’t want people to think ‘she’s going to be a waste of time because she has just come out of hospital’, I didn’t want any of that but I ended up doing more work than I should have been doing really. I ended up doing heavy work and cleaning and I started losing weight and then it started affecting my health...

Kate decided to make a career change, but one which suited her better and was more appropriate to her changed identity and capabilities:

I must admit, I did find the massage draining and I realised it wasn’t actually doing me any good, I then felt that the ...[other] work wasn’t challenging enough mentally and so I went to college and did some training on computers and customer service courses... and it was one of my friends that told me there was a place at the tourism centre...I love it, it is very varied ... I do 3 days on and I have 3 days off which I find about right it is about balance, isn’t it?

For Margaret, her work (in retirement) was co-facilitating a support group for cancer patients. She recognised that she had to manage the information that others had about her and how they viewed her post-diagnosis, but the decision to disclose was taken out of her control:

There is one member of the group that annoyed me a little bit by sort of telling everybody straight away [about her diagnosis] but yet it got it out of the way, I suppose...once or twice I have thought I wanted to give it up and I still feel that way sometimes and then I will go along and I will help someone or talk to someone and then I think well, I have done some good today...

Robert, like Margaret, also faced the problem of private information in the public arena, and of how to manage this:

So the general story I was telling people was that there were people that knew I had a haematological issue ... I... didn't want to give them my diagnosis and the main reasons were that firstly I was protecting myself because I was very cautious about the amount of information I wanted to know about my illness and also I didn't want them looking up details about my illness...I wasn't protecting them particularly I didn't want them to know more than me...on top if that I had a man who had cancer himself and so that became quite a situation , I had a female team member whose husband was diagnosed with cancer and probably other things, but at one point it felt that everything was negative...anyway, I stuck it out...

Robert's decision to give up work had financial repercussions, but he considers that it was the right thing in the circumstances, although he realises how this affected his feeling about himself as the main financial supporter and 'breadwinner' in the family:

I think my self-esteem comes from my family and I think that I get worried about finances and I know that we are living on borrowed time in a way and that it has put me in a very awkward personal situation...Having a serious illness is one thing but saying. "look, we are not going to be able to go on holidays' you know and also D is on a 4 day week and I feel that I would much rather she survived and enjoyed her work on a 4 day week than pushed herself to the limit

Dee, who had worked in a supermarket at the time of her diagnosis, found that her employers were very supportive but was forced to give up work, not only because of the physical nature of the job but also because of the effect that the diagnosis and treatment had on her emotionally:

I actually gave up work just after my radiotherapy. I worked in X at the time and there used to be quite a lot of lifting getting the trays and all that and I felt quite emotional and so I decided to stop work. I must admit, they were very good as a company, they were helpful. I stopped work but I used to take myself to radiotherapy.

Dee re-trained as a beautician, a job she had always been interested in and which represented for her a new opportunity as part of her life post-cancer. However, she had to negotiate her identity as a woman with one breast, which meant that she

perceived herself as being different from other women on a residential training course, and having to make a decision about self-disclosure:

...in the past I have had a bedroom to myself because I didn't want to have to be getting undressed in front of somebody...And [this time again] I had a bedroom to myself. But then again, all the other girls wanted to know why I had got a bedroom to myself...and I think 'why should I have to keep explaining myself?'

Dean went back to work as soon as possible after his initial treatment, but for him this was a positive decision and he was given the support he needed:

Work were fantastic...anything I needed. I have 2 major bosses above me, but obviously I am a boss myself, I have people under me, and so my superior was absolutely cracking, anything I needed...I have another guy who I used to work under and he called me and said '...anything you need, you take it' and I was told I could have as much time off as I wanted because ...with the chemotherapy I was missing a few days when I was poorly and I was on full pay, so I was pretty lucky...anytime now when I need time off it is not an issue..

Having seen how the respondents negotiated their relationships with family and friends and, where relevant, in the workplace, we come to the final section, where respondents consider how or whether the experience of cancer has changed their lives.

New Perspectives

The final theme that emerged from the accounts of the respondents was that the experience of cancer seemed to provide the impetus to make a fresh start, to take on a new identity and new challenges. Some of these changes and changed perspectives were temporary but some were more permanent, for example, a change in career, a new way of relating to others, a different attitude to life. Many spoke of being less anxious about the minutiae of life, of being less concerned about what others might think and not letting other people have power over them. However, although the respondents experienced these changes as generally positive, they were tinged with the fear that the cancer could return at any moment which left a sense of

vulnerability which was not always recognized or acknowledged by others who had not had that experience, and which thus set them apart from others in society. Although most respondents felt that their lives had changed irrevocably because of their experience of cancer, others seemed to ‘take it in their stride’, to view it as just one other life event that needed to be managed but that did not warrant any special treatment or significance. Some respondents debated the new identity which they felt had been conferred upon them, that of cancer ‘survivor’, and whether or not this ‘fitted’ their own experience or was instead another form of categorization which excluded individuality. Some respondents are able to use their experience and new perspectives on life to help others both personally and professionally and to make recommendations about cancer care services in the present and future

Living with and beyond cancer – the issue of survivorship

Regarding the term ‘survivorship’ itself, David was quite scathing:

A lot of the patient community that I talk to are accepting it because it is there as a common word and by that I mean that it is an acceptable phrase. It is a bit like prevention, but actually when we use prevention we can’t say that if you don’t smoke, don’t drink, go for runs, eat the right food, it is necessarily going to protect you, so taking all the prevention initiative isn’t a guarantee. Survivorship isn’t a guarantee that you will survive, so the phrases that are used that I think the patient communities like better are ‘living with and beyond’...I don’t like survivorship as a word, but I am happy to live with it as a co-ordinate...

David gives reasons his preference for the phrase ‘living with cancer’ over ‘survivorship’ as he feels it better describes the situation of the majority of people who still experience the after-effects of cancer, either because it is impossible to remove, or because of the effects of the treatment have in some way compromised the person’s future health:

with some cancers you will constantly have the cancer in your body...These drugs are letting people live much longer but the cancer is still there and it keeps trying to get in somewhere else, so how do we stop that? That is for research. So people will live with it because of the new drugs. Then there are

people like me who have had the cancer and they live with the consequences. There is a third group who, having had the treatment, the causes of the treatment such as intense radiotherapy affects the bones and for me there is a good possibility that I will lose my teeth or I may get cancer in my bone because of the intensity. I may have 20 or 30 years or it may not happen. So living with it is a much more comfortable phrase...

David is able to make a comparison between survivorship and victimhood:

‘What happens is you get told you have cancer and suddenly people are doing things to you and for you. Somebody said to me that ‘the thing is people open doors and it irritates the bloody hell out of me’ because actually you are made to be a victim and then you are forced to be a victim because you go to open the door and people go ‘oh no no no, here let me open the door’ I mean in a philosophical sense, it is not just the door itself...

David speaks of the concept of survivorship as crude, without nuance, a word that is used to label people without actually describing their lived experience:

There is the crudeness of it, I would never define myself as a ‘cancer survivor’ despite having 13 years, I would see myself as someone who was treated for cancer. So it is a whole new set of phrases... There are people who are threatened by cancer, there are people who are treated for cancer, there are people living with cancer, and there are subtle [differences]... that is why they use ‘affected by’ to include carers, treated for is about the patient... I can’t go to meetings saying I am a cancer patient, 13 years ago I was treated for cancer so it is about breaking down those phrases.

Mo rejected outright the application of the word survivor to her own situation:

...My reaction was that it was a short term problem and I would be fine for the next 50 years, I never thought that I would die and I still don’t think that I will.. If there was a recurrence of it I might feel differently... [the word ‘survivor’] ... is not a word I would use because survive suggests to me that I could have died and that was never an option for me... cured would be the word I would use...

Gwen also rejects the term ‘survivor’ but for different reasons:

I do not think of myself as a survivor, indeed there is never a day goes by without the nagging feeling of ‘what if it comes back?’ This is the price you pay for survivorship. However, this can also be construed as a positive as it is a strong reminder to beware of complacency.

Cancer was associated in Dee's mind with inevitable death. However, with the benefit of hindsight, Dee has revised her opinion on the meaning of cancer, and seems to put herself into the category of 'survivor': "I think, like a lot of people, that when you hear the word cancer it seems like a death sentence but I mean, ten years on, I know that it is not...."

New Directions – 'Being' Differently

Bill derived support and meaning from his involvement in the Cancer Network and in a sense became a 'professional' patient...although he rather fell into it by accident:

I went to an oesophageal patients' meeting and there was a lady there...and she ran the Cancer Forum for the local Health Authority...and she was looking for volunteers and she came and she gave a little talk and she asked for volunteers and I kind of felt sorry for the lady because nobody went near her...I gave her my name and my address not thinking that anything would come out of it...A few weeks had gone by and then I got a phone call saying "Bob, would you like to come to one of our meetings? And I thought that I would and I have never looked back since..."

Through the Cancer Forum, Bill was reunited with a friend from Scotland, who was also now living in the Midlands with cancer, and for him, involvement in the groups was a source of both friendship and support... "I have built up a right good contact of networks and friends..." although he still maintains this is more by luck than judgement, which would seem to accord with his new philosophy in life, developed post-cancer: "nothing has been planned, it is just evolution...I just go with life, I don't fight it, I just go with it..."

Through his involvement with the cancer forum and 'knowing the right people', Bill realized that he was not receiving all the help to which he himself was entitled, and was able to rectify the situation, including being referred to an oncology dietician and receiving further pain management assessments. He was also instrumental in campaigning for the needs of local people living with cancer by advocating for the establishment of a support centre in his town.

Lisa, too, re-assessed her priorities and came to some decisions about how she was going to spend her time: “I guess I was feeling that my life was going to change. Work is not going to be the top priority any more. And I decided that I would concentrate more on relationships, relationship-building.” Lisa in fact set up a cancer support group in her local area with a group of women from her Church, all of whom had been diagnosed with cancer.

Susie became aware of a sense of appreciation of life and the small kindnesses of others : “I find that I get thrilled to bits if anybody buys me a bunch of flowers...Everything is appreciated, from even a small amount of help...”. She has also learned from a brief period in hospice day care following recurrence of her cancer to manage short term relationships with others who are experiencing life-threatening illness: “That is the hardest thing, I think, to say goodbye to somebody but we have learnt to compress a brief friendship and make it blossom...”

Jo also describes her motivation to make a radical change in her lifestyle as a result of her cancer experience and her desire to improve service provision for people who had undergone a similar experience:

Setting up a free counselling provision for people affected by cancer was motivated by my own cancer experience ...and the lack of support in my area. I hated the thought of other women being alone with the insurmountable fear I felt when diagnosed with cancer

Jo and Gwen (one of my other respondents) also went on to co-found a theatre company, which includes in their repertoire a play written by them both about the experience of living with breast cancer – they act the parts ostensibly of themselves in order to raise awareness of living with cancer, and to help improve communication skills between the cancer patient and health and social care professionals to whom they perform.

Robert, too, is able to reflect on what has changed for him:

Well I think that giving up my job and deciding that I would dedicate myself to the family was part of that...I think that my personality had been as a person who is...socially I like to keep myself to myself a fair amount of the

time and consequently I am kind of perceived as not being that generous or giving, well the same thing really.. and I did kind of think that I perhaps need to address that...One of the kind of funny things is that friends of [my son]'s have commented to their parents that R [Robert] is much nicer now (laughs) and I just think that is great...and also giving myself time and space. I remember, you keep the images in your head, we have a dog at home and I would always race her around the block before going into work and I remember one day being on the train into Leicester and seeing this guy walking with the dog in the fields and thinking 'I wish that could be me' and then it was me.

David speaks of his involvement in the Expert Patient Scheme, of what he learned from others living with life-threatening illness and how it helped in the need to find purpose and meaning in the new territory and changed circumstances of life-threatening illness:

Again the same thing what it is doing is giving people those skills and knowledge. I heard a fantastic patient who talked at an expert patient event where he said 'I was a farmer and I had a major heart attack, suddenly I don't just lose my job, I lose my life. I lose my farm, I lose my job, lose my work and I am suddenly living somewhere else and I am worthless because everything that I did is gone' and he said 'all I did was sit there and moan and had it not been for the Expert Patient Programme I would have carried on in that mode. It gave me a purpose and a meaning for life and an opportunity to change and an opportunity to realize I was just a miserable bugger'. My wife turned around and said 'since you did the Expert Patient Programme you have changed completely because you were just lost'.

David used his previous experience of work as a teacher, undergoing Ofsted inspection, coupled with his experience of illness to campaign for better service provision, which he would not have done had not cancer intervened in his own life.

I started then to go and give talks to professionals about what it was like to be a cancer patient and instead of doing a 'oh, this was how it was for me, it was bloody awful' which some patients do, I came across with something different. I presented some of the stuff that was really good, here was some of the stuff that could be done better and here are the things that should be inspected. I was trying to promote celebrating investigation, don't try saying that you will do something strategically and when the inspector goes round the corner it is over. So I can see in hindsight that that was what drove people to say 'D, would you join that committee or this committee' but again, how do we make sure that we get people's experiences of something and we help them crack the experience. Don't just come in and tell a story,

but actually tell it, reflect on it, choose moments and then think about how you can change services...

David felt that he was ideally placed for his new role, transferring his skills in teaching and training to training patients to be trainers:

I had started to talk at conferences and I have got involved with Cancerlink, which is part of Macmillan Cancer Support, where they go and train patients to get involved in their service. I am one of the trainers and up until 2002 they employed trainers because they liked the safety and distance and I persuaded them that actually, given my background, I could work with people and empower them, it is the people that have been there that you want to teach you.

David questions how society estimates and values a person's value and worth, particularly in relation to welfare benefits for people with disabilities, but feels that the money which he has earned since his diagnosis with cancer since his experience of cancer is worth far more than its monetary value:

... if you were to draw a graph you would see my pay go to half and then supported by the benefits and then my pension which isn't huge, it is very very little, it is more than £70 but it is not a lot of money and I spent the lump sum because we survived as a family 2 or 3 years on, but actually if you looked you would see the graph went down and my earnings from my company, I don't mind saying that, in year one was £3,000 and it was the best £3,000 I have earned in my life...

It was very important to David to see his recovery from cancer as an opportunity to make a fresh start, and he attributes much of his success in life to his experience of cancer:

of all the things I have done since then...oddly, none of those would have been done without the cancer...

The most part of my experience I would say was positive. It did utterly change my life, there is no doubt, I would not be doing any of the things that I have done and it is thirteen years on that I still pinch my skin and say 'is this really happening?'... If somebody had said to me when I was going through those dark, dismal days that you would achieve and go to Downing Street and that you would be in Buckingham Palace and getting awards... you would never believe that you would be doing those things and you would hear that someone had got cancer and then you would look at their background and see 'doctor, who got cancer' or they were a researcher or they were a chief executive...you would see the words 'chairman of this, or chairman of that and I can see now that people would look at my CV and

think that I have done a lot of things and I have, but the route of them was the cancer...

For Dean, the experience of cancer motivated him towards fundraising, but it was seeing the example of those who he considered to be less fortunate than himself – that is, children with cancer – that gave him the encouragement he needed to get through:

I have done a lot more fundraising and I think, when I first got diagnosed with this I was seeing people, especially children, in the unit with this disease...but what made me decide, I can't really put my finger on it, but I thought, I remember this little girl and a little boy, and they sat opposite in a corner and the little boy had got no hair at all and he was just playing as if nothing was bothering him and I thought 'he is having the treatment and he is getting on with his life' and I thought 'right, well why would I sit here and be negative and un-positive about things that I could do?' and I thought 'right, well, I am going to give something back'...

Fundraising for cancer was a new departure for Dean and it represented a direct opportunity to 'give something back': "I gave F [leader of cancer support group] last year a cheque for £200 for the group...F was absolutely amazing the first year I was very poorly. She sent us a cheque and she said 'please, take the children and have a day out' and I will never forget that (laughs)..."

Kate speaks of having cancer as a transforming experience, and one which she conceptualises as a time of growth, of giving birth to the opportunity of a new life:

the experience of going through the cancer, it transformed me in lots of ways I always remember reading about this lady in one of Segal's books and I remember thinking 'this is just the way I felt..' ... basically she was saying that it was like going through a pregnancy when you have cancer, it is like you go through the challenges and the uncomfortableness... but also... a journey and it was almost like her treatment was 9 months and she said it was almost like being reborn, like going through a birth or giving birth... There have been challenges afterwards, but I think it is I have heard people say this before but I really wouldn't have changed it I wouldn't like to go through it again in a way, but I wouldn't have liked to have missed out on it either...because it was a growth period, it was an awareness period, it gave me time to stop and re-evaluate and reassess. I am still doing that even now...

Kate recognises how her attitudes to other people have changed, particularly her ability now to empathise with people who have experienced health problems:

One of the things I must say because I had never ever in my 36 years had any health problems whatsoever and some people I had come across in my life had had health problems by that stage or didn't have as much energy or whatever and I used to criticize or judge them whereas now I can actually sort of feel I try and put myself in their shoes and think 'well, hang on, how would I actually deal with that?' Hopefully I have changed in that way....

For Teresa, the experience of cancer will always be present in her life: "The feeling of 'what if it comes back' has never left me. It is less acute as time has gone on but it hasn't really gone away, not really. It is not there every day...."

However, despite her feelings of vulnerability, Teresa found that, after a while, she was developing a new strength, that she now put herself in more challenging situations, particularly at work:

I am not as frightened of going [changing jobs] and I am not as frightened of getting outside of that comfort zone and pushing myself out of my comfort zone... I think after I had cancer, I did become a little bit more dependent on my husband...and I stopped driving and stuff like that and I completely lost my confidence. In the past two and a half years I changed my job and it meant actually using a car for my job and so I actually bought myself a car and overcame that fear. I do put myself in challenging situations I suppose to prove that I can cope with them...I think... in a way it has given me confidence

She finds that she is more assertive, that she will not 'put up' with things, that she has more of a sense of the courage of her own convictions:

I am very sensible actually, very practical, I think things through. Another thing that I do is if I don't want to do something now I will not...I am more my own person and also I, guilt, I can't be doing with it anymore because I spent a lot of time feeling guilty...and also thinking that when I have made a decision, I say to myself, 'that decision that you are making now is that right decision for this time and when you look back on it, you must not look back on it and regret it'

Teresa explores other ways in which she feels her life has been enriched by the experience of cancer, that it has given her a greater appreciation of the natural world and things that money cannot buy:

Well, that is why when I talk about having been through it I think I have drawn positively from it and my life has been enriched, this might sound weird...Heightened awareness of the blue sky and autumn and birds and I can get very emotional over things like that, I can get really carried away by their beauty...

Teresa feels that she is a 'better person', with a greater awareness of herself and others and the ability to help others from the lessons she has learned:

I do think there is a softer element to me...I think sometimes, and that is another thing really that I have learnt, and it is something that I had...you do find out about people and it is learning not to be judgmental and understanding that other people cannot perhaps do what you yourself would do and I had a little mantra, which is 'accept what you cannot change'...and I had that there and there was something else which I have forgotten now, but I did have them literally pinned behind my bed because that helped a lot, I did have the mantras because I couldn't afford to get stressed over things like that.

Gwen has also noticed a reduction in her levels of stress since being treated for cancer: "Cancer is an emotional journey but [it]...has helped me to live my life in a more honest way, taking time to make choices and to alleviate as much stress as possible from my life"

For Bill, the changes wrought by cancer undoubtedly had a life-changing immediate effect on his life, but he feels that the changes in someone who is living with cancer can be more evident in the long-term:

I don't know, I honestly don't know about anybody else but I can only be honest with my own experience and I think that irrespective of whether someone is diagnosed with cancer, it changes every aspect of their lives and sometimes they don't realise it until many years later. It is an on-going thing.

For Bill, the experience changed his life in what could be considered a positive way- he felt that he had not changed completely but that he now had a different attitude to himself, a different way of dealing with life, with less anxiety and worry:

It was something you said earlier about people , how it affects them, spiritually or whatever, with me I fear nothing...Honest to God, I fear nothing and no-one now...It is because I have been somewhere that I never ever thought I would go. Life today is just getting through the day, and I don't say that because it is an ordeal to do that, I just sail through the day. Things that were important are no longer important as long as I am okay and my health is okay, to hell with everything...

Bill also links his experience of thinking that he was going to die as something that 'marks him out' from others, that sets him apart from those who haven't had that experience, the difference between talking about death and really thinking you are going to die, or being with someone who thinks they are going to die and seeing the effect this has on them.

What I am saying ...is I reached a point and with hindsight I could see that I had been somewhere, do you know what I mean, people talk about death and I have seen it. I remember lying in the hospital and I had been operated on and then I was in intensive care and then they took me out of there and put me in high dependency and the surgeon who had operated on me when he came round on his rounds, because there were only 4 beds in this little bay, and he said to 2 guys 'I am very sorry but there is nothing I can do'...honest to God, it was like watching a shadow come down over them, just like that...That was the switch off point...

It would seem that there is this sense of being in different 'camps', one for those who have never had to consider their own mortality, one for those who are confronting death on a daily basis and one for those who have had their lives threatened in some way but have continued to live.

Overall, however, Faye would say that the experience of cancer is one she would not have missed, as she felt it had taught her lessons in how to live, about living in the moment:

I know this sounds really odd... but I think the experience of having breast cancer was one that I wouldn't want to have lost... I actually think it was one of the best things that could have happened to me... it changed my life. The silly little things that would have bothered me in the past like being late to get somewhere and worrying about traffic, all this just goes over me now and particularly for those two years every living moment you have, you enjoy it, everything is special. Going to my kids' plays and seeing them in their harvest festivals it was just like 'this is fantastic!'

Faye's new perspective of having been given a fresh start and appreciating life in a new way does seem to have been temporary- maybe it is impossible to maintain, to live with such an increased awareness:

As time goes on you do get, as I said to my mum the other day, I wish I could get the feeling back that I had the first couple of years and I can't believe I can say this, because I almost feel like I have drifted back into my old ways because I am certain I am going to survive and therefore some days I do get cross with the kids and you, sort of thing, I miss that time that I had when everything was so wonderful and you saw good in everything and everything was special. Partly I sort of think 'I have slipped back into my old ways a bit'

Faye has her own 'take' on survivorship, or living beyond cancer:

...that is part of survivorship, that is what they were saying to us, that is a good sign and it means you have got on with your life and you are not waking up every day and thinking 'oh, I had cancer' or 'I have got cancer'. I have got on with my life and it doesn't preoccupy me. It is really hard to describe it because some days you wake up and you almost forget that you did have cancer. It is so 'in your face' at the moment anyway, there is cancer everywhere and the word cancer springs up and you sort of think 'blimey, did I have that?' My life will never be the same again but I can't say that it is a bad thing. I am hoping my life will never be the same again but in a good way. There are certain things that, after that experience, that I want to take on. I do think that it has changed me for the better, yes...

Living with Cancer – Exploring the Myths

David is now more aware of the societal myths surrounding cancer, the fear of cancer and still thinking of cancer as a killer, which he attributes to a lack of awareness of the changing face of cancer care and treatment:

It is about lack of awareness and lack of knowledge, it is all of those factors but to a great extent it is fear and denial because we still believe that cancer can kill us and when we hear the word most people will think ‘oh, no, I am dying’ and so you know, we were talking about perception of the city in terms of crime and actually how people think about things, so the perception of cancer is behind the reality for some people...

David is also aware that it is impossible to generalize about cancer and its effects because there are many different types of cancer which will have different outcomes, thus pointing to the need for individualised service provision:

Of course I live with it on a daily basis because my voice is so damaged so I have to confront it. People that have had blood cancer, there is nothing there, for example, for somebody with breast cancer it is all to do with self-image and it is kind of odd because we are still talking about one disease but lots of variations and very different outcomes. So progress had been made with some, and some still, you know...

S “and so that fear still holds for some people?”

D “Absolutely...It is the individual....”

David makes links with changes in government policy and cancer services and how things have changed (for the better?) with increased patient involvement since his time of diagnosis and treatment: “So now we have got Lord Darzi saying that quality has got to be at the centre of everything ...there are real shifts now where the customer becomes king or queen in the sense of how we deliver things...”

Thus the respondents were able to conceptualise their individual experiences of living with cancer, from medical intervention having first realised something was wrong, to examining their relationships with themselves and others, and coming to terms with what for some was a changed identity as a ‘person with cancer’, to coming through the experience and ‘living to tell the tale’ about what they had learnt from the experience of cancer. Some common themes have emerged which I will explore in more detail in the next chapter, Interpreting the Findings, in relation to the theories identified in the Literature Review and findings of related studies, which relate to the emerging themes.

INTERPRETING THE FINDINGS

Beware Sagacious Messengers

“In the face of cancer there is a compulsive desire to identify the ‘net gain’...this is the romance around death and dying that confers obligations on those who have visited its borders to return with a new understanding, a knowledge that will make life bearable for everyone in the face of much-feared finality” (Stacey, 1997, p 244). “Cancer narratives frequently offer such reassurances. They belong to the ‘net-gain’ narratives which we like to tell ourselves in the light of misfortunes. The gains somehow soothe the wounds caused by unexpected trauma. This can lead to the familiar cliché ‘cancer was the best thing that ever happened to me’. According to this version we become wiser as we approach death...The person who has had cancer is presented as a sagacious messenger whose purpose is to remind everyone of the preciousness and precariousness of life. The so-called ‘survivors’ of cancer are seen to possess knowledge of the secrets of life, as well as the secrets of death. They are heroised for their confrontation with death, which is presumed to have enlightened them about how to live life. They are bearers of knowledge. *They have lived to tell the tale.*” (Stacey, 1997 p 244-245).

Stacey’s depiction of people who have survived cancer (above) is certainly thought-provoking, and to some extent accords with the accounts of my respondents, given in the previous chapter. There is certainly a sense that, for some, the experience of cancer has been one which has been instructive and there are depictions of life having changed for the better. In their research into women’s experience five years after treatment for gynaecological cancer, Sekse et al (2010) also found this mixture of hope tinged with apprehension and vigilance: “the long-term cancer survivors experienced profound changes in their lives to which they all needed to adapt. A reorientation in life and a revitalization of values appeared as a new presence and a deeper connection with the world, other people and oneself.” However, despite the possibilities for personal growth which the cancer experience seemed to provide, a sense of vulnerability pervades many of the accounts, and a deep gratitude for being alive seemed to exist alongside “living with a kind of preparedness – always alert or ‘on guard’ - in case cancer might return” (Sekse et al, 2010 p 289).

Despite the fact that in my study I did discover some ‘sagacious messengers’, who clearly (in hindsight?) conceptualised their experience of cancer as life-changing and having given them a positive message that they wanted to impart to others (for example, Dee and Kate), it was apparent that for a number of respondents the experience of cancer was characterised by the fear and uncertainty described so graphically by Craib (2003, see earlier in my thesis, p32) and which, as he suggests, is seldom acknowledged in academic research and narratives of cancer that are available in the public realm. Dean, for example, mentions fear a number of times in his account, and even David, who in many ways could be seen to have had the most ‘life-changing’ experience as a result of his encounter with cancer, does not deny the sense of fear and uncertainty he also endured.

Interrupted Biographies

One of the main theoretical frameworks which has been used to define the experience of living with cancer is that of biographical disruption (Bury 1982; 1991, 2001; see Literature Review, above, Part One).

As the stories in the preceding section confirm, the majority of the respondents in my study would seem to have experienced a major disruption in their biography (for example, a change in career for Bill, David, Dee, Kate, Jo and Gwen, and a change in lifestyle for Faye, Susie, Lisa and Kate) with a marked effect on their sense of self and their body image and their need an ability to construct a new ‘post-cancer’ identity (for Dee, Gwen, Jo and Faye, in particular). However, both Beth and Margaret and, to some extent, Fiona, seem to have ‘sailed through’ their personal experience of cancer relatively unscathed - their life course or ‘biography’ seems not to have been disrupted in any way by their experience of cancer and their lives have continued in much the same way as before: they could be defined as having experienced Faircloth et al (2004)’s ‘biographical flow’.

The Significance of Age

I conjectured that this could be attributed to their age (these respondents – Beth and Margaret - were among the oldest in my study, and neither were of working age when their cancer was diagnosed).

Foley et al's (2006) research would seem to bear this out: they found it was more common for individuals who had received their diagnosis at a young age to refer to it as a "life-changing event, something that had reshaped their outlook on life and, in many cases, led to changes in work or personal relationships" (Foley et al, 2006, p 254). Deimling et al (2006) conducted research with older adult long-term survivors of cancer, and found that, although this group were more likely to express cancer-related health worries and vulnerability to cancer than their younger counterparts, "For most older adult long-term survivors, the legacy of cancer continues in terms of health worries [which may be appropriate for their age] but does not dramatically compromise their physical or psychological quality of life" (Deimling et al, 2002, p 319). Zebrack et al (2008, p 897), in their study of quality of life for long-term survivors of cancer, also concluded that "mental health and quality of life are less often disrupted in older individuals, possibly related to greater life experience with stressful events and learned coping skills as a result". Fiona, the oldest of the respondents at the time of interview, was determined to stress the discrimination she felt she had experienced on the grounds of age and the 'battle' she had to undergo for rehabilitation, but was nonetheless accepting of the outcome and acknowledged that cancer was prevalent in her family – a significant number of her relatives had experienced cancer and there was a sense in which she was expecting it to be visited on her.

The Significance of Spirituality and Meaning-Making

However, what could be seen as a protective factor for all these respondents – Margaret, Beth and Fiona – and which could account for their apparent acceptance of the situation, was their Christian faith. For Fiona it was the belief in an afterlife

which gave her hope and reduced her fear, whereas, for Margaret, it was the prayers of her local Church members.

The faith or belief system which was deemed to be supportive and helpful in managing the experience of cancer was also reported by a number of younger respondents, for example, for Brenda, although she qualifies her experience of support from Church members to have vastly increased once she was diagnosed with an illness they could understand, rather than the mental health difficulties she also experienced. For Robert, faith was a personal matter, it gave him strength, as did Mo's adherence to Quakerism and Jean's to Buddhism. For Faye, her Christian faith meant that she felt part of a community of believers, who she found to be supportive. Both Lisa and Fiona had encounters with Christian medical professionals who shared their faith and were prepared to disclose it, which both respondents found helpful.

Spirituality was a common secondary theme in Foley et al's research into long-term cancer survivors, but, unlike my respondents, they found that most individuals who felt they had experienced personal growth linked this directly with spiritual growth, indicating that they had "grown spiritually and developed a deeper appreciation or commitment to their faith" (p 252). Halstead and Fernsler (1994, cited in Breaden, 1997, p 983) found that in their study of 59 cancer survivors, over two-thirds of the people thought that prayer or a belief in God was a very helpful strategy in survival. However, in my study, the theme of personal growth, which characterises many of the accounts of my respondents, cannot be attributed to any particular belief or faith pattern, as it was observed in those who professed no faith as much as in those who did. I conjectured as to whether it is the ability to find meaning, to make sense of traumatic events or adverse circumstances, rather than a faith or belief in a certain religion, that makes the experience of survival more bearable (Taylor, 1995; Carter, 1993; also Frankl, 1963). However, it would be wrong to place this need to find meaning in the experience of ill health outside the realm of spirituality: indeed, meaning-seeking and meaning-taking are core components of the contemporary discourse on humanistic spirituality. "There is probably not a definition of spirituality in contemporary discourse which does not include within it the *search for meaning*" (Holloway and Moss, 2008, p 110) and, according to Canda (2008, p

27, cited in Holloway and Moss, p 31), in essence “Spirituality...refers to the human search for a sense of meaning...”

Confrontation with one’s own mortality is one of the most challenging personal experiences in which the search for meaning is common across world views, be they secular or religious (Holloway, 2007, in Holloway and Moss, 2010, p 31). A recognition that the discourse of spirituality can be both religious and secular (Holloway and Moss, 2008, p 28) can inform our understanding of the universal need to make sense and meaning of adverse life circumstances. Likewise, an understanding of the concept of transcendence as one in which a person can be helped to transcend a problem or pain even though its source cannot be removed (Holloway, in press), links to my earlier discussion of the relevance of social work practice to the situation of people living with cancer as a chronic illness (see earlier, p16; also Everard, 2005; Reith and Payne, 2009). Indeed, for Canda and Furman (2010, p 315, cited in Holloway, in press) a social work practice which embraces spirituality can also be transformative: “...it includes, but is more than, problem solving. It includes, but is more than, promoting coping, adapting, or recovery...When change is transformational it moves people forward on their life paths.” Thompson (2010) also makes this point, observing that “spirituality is fundamentally about meaning-making” and he also links this directly to social work practice because of its emphasis on “helping people develop more empowering meanings, understandings, or ‘narratives’ ” (Thompson, 2010, p 142, cited in Holloway and Moss, 2008, p 7).

According to Heidegger, anxiety for one’s own death, and thereby the experience of existential loneliness, can cause fundamental changes in people’s lives: this is the case even in survivorship, where a feeling of vulnerability may remain – the concept of death salience as described by Little and Sayers, 2003, in Literature Review, earlier, p 32) .The stories of my respondents are, however, similar to those of the women in Sekse et al’s study who, having been confronted with their mortality, seemed on the whole to have exchanged, in Heidegger’s terms, a somewhat inauthentic life for a more authentic life, thereby being empowered to become more truly the persons they are or want to be “... this experience of facing an existential ‘tremor’ led to personal growth. Their cancer stories revealed that they felt ‘more

alive' and closer to 'people, their surroundings and to their own lives in a more profound way" (Sekse et al, 2009, p 293).

The Significance of Gender

In their study of long-term cancer survivors, in which comparison was made by type, gender, ethnicity and age, Foley et al (2006, p 253-4) found that women were more likely than men to identify positive aspects of cancer survival, "especially with regard to expressing a greater appreciation for life, moving them towards a more fulfilling existence, and a commitment to the greater good through volunteerism [but that] Men reflected upon the cancer experience in a very matter-of-fact manner. They acknowledge and respect that it is a part of their lives, but indicate that cancer had neither positive nor negative long-term implications on their quality of life." This was not the case in my study, however, where men possibly spoke more fully than women about how cancer had changed their lives in very active ways, by becoming more proactive, inspiring them to 'give something back' (Dean), for example, by becoming patient representatives in campaigning groups to improve cancer services (Bill and David).

The Significance of Cancer Type

Additionally, Foley et al (2006 p 253) found "No differences in themes were observed by cancer type or race/ethnicity in how individuals interpreted the cancer experience". This I also find surprising. I could not comment on ethnicity –I recognised that this was a limitation in my study, which included few respondents from ethnic minorities, and, although I did have Scottish and Welsh respondents, there were no discernible differences between these and other respondents, which could be attributed to the fact that they had received treatment and were living in England at the time of the study. However, in my study, the type or site of the cancer seemed to be highly significant in terms of how people were affected by the experience. For some respondents, the effect of cancer was very visible, for example, women diagnosed with breast cancer who had undergone a mastectomy

had to make a highly significant decision about reconstruction (including Faye, Teresa, Mo, Dee, Gwen and Jo); also David, whose voice was radically changed after his surgery, could not hide this fact from those around him. There were issues for others with less visible cancer sites, for example, Dean knew and had to live with the fact his brain tumour was too dangerous to remove and that the likelihood of it growing and causing further problems was ever-present and Robert was also debilitated by his blood disorder. Thus for a significant number of respondents it is evident that the site of the cancer was highly significant in terms of how the individual was affected by it and managed the identity it conferred (Charmaz, 1994).

The number of respondents who felt that cancer was in some sense inevitable because of their lifestyle or issues of heredity is counterbalanced by those for whom cancer came as a complete shock, because of their previous state of good emotional and physical health. However, without exception, the respondents had 'lived with' some sort of discomfort or anxiety about their health before seeking medical advice, and often only had done so on the prompting of a friend or family member. It would seem that there is an understandable reluctance to move from the safety of the 'healthy' status to the acknowledgement that something 'might' be wrong and to put themselves in the position where their worst fears may be confirmed, which may seem surprising given the health promotion campaigns which encourage early detection and treatment, and of which this group of people would undoubtedly have been aware.

The Significance of Occupation

Issues of work and occupation were relevant to a number of respondents of working age and who returned to the same workplace after their treatment for cancer and who identified changes in their ability to work, and in how they were viewed by former colleagues who and known them previously and also by more recent colleagues who had not known them prior to their illness. The difficulty of 'feeling' different but not wanting to be given preferential treatment was significant, bringing with it the dual identity of survivor and victim, and the issue of not always being in control of how others view you. The discussion of the relative cases of Inglefinger (1980) and

Broyard (1992) in the section on Liminality (above, in my Literature Review ‘Becoming ‘other’’) is of relevance here, as is Cayless (2009)’s recognition of the dearth of cultural scripts upon which the person living with cancer can base his or her actions.

The Significance of Others - Roles and Identities

Of note also is the extent to which the respondents chose to identify themselves with the ‘cancer community’ or to pursue their own course through the phase of illness and carry on with life as normal. Some displayed the ability to move between the two worlds (that of the ill and that of the well), for example, Faye, who by turns identified with and supported her friend who was dying from cancer, but also chose to keep a part of her life separate from the experience, by not disclosing the fact of her cancer to a certain group of acquaintances. As we saw in the previous section, when Faye refused to remove her wig even in the steamy environment of the swimming pool as it would then ‘betray’ her by disclosing her identity as a person with cancer, the uncomfortable effects of the action were outweighed in Faye’s mind by the fact that by doing this she was accepted as ‘normal’ by the other parents and could preserve her pre-cancer identity (as explored in the Literature Review (above) on Biographical Disruption- Identity and Loss of Self (Bury, 2001; Charmaz, 2004). As also explored in Chapter One, The Special Case of Cancer, the status of cancer sufferer – or even, one might argue, cancer survivor - is stigmatised and is likely to raise fear and anxiety in those who have not had a similar experience. According to Goffman (1990, p 141, in Exley, 1999, p 153), therefore, Faye’s behaviour in this case could be seen as a societal expectation: “When the stigmatised person finds that normals have difficulty in ignoring his failings, he should try to help them and the social situation by conscious efforts to reduce tension.”

This can also be seen in Dean’s actions in wanting to protect his children from a knowledge of his diagnosis, and Robert’s behaviour at work in not disclosing his health problems to his colleagues: “For many respondents the emotional work they were involved with was similar to Goffman’s concept of covering, whereby individuals who are both aware of their stigma and prepared to accept it ‘...may

nonetheless make a great effort to keep the stigma from looming large” (Goffman, 1990, p 125, cited in Exley, 1999, p 125). Thus individuals appeared to want to detract attention from their own status, not only to maintain the illusion of ‘normality’ but also to reaffirm their own more valued identities of parent or manager. Kagawa-Singer also found this attitude in her research with people living with cancer, and quotes one of them as saying: “I am really very healthy, I just have this problem, but I am still me” (1993, p 295).

Susie also recognised that she needed to be careful when making new friendships with other people who had cancer, as she knew that the friendship was likely to be threatened by time. Young et al (1999) examined friendships among women who had been diagnosed with cancer and their friends, and concluded that this is a complex area of negotiation and re-negotiation, where some women deliberately made new friends - “friends for death, so to speak” (Young et al, 1999, p 269) - with the possibility of ‘survivor guilt’ when death came sooner for one than the other. The uncertainty around managing friendships for my respondents is linked by Young et al (1998) to the concept of liminality, in that the sense of living ‘in limbo’ means that the normal ‘rules’ governing friendships and other social processes do not apply and new ones must continually be negotiated.

The presence of friends or relatives who had themselves experienced cancer is an enduring theme throughout the accounts, and it is evident that the treatment and outcome experienced by the previous generation had influenced how the current generation received the news of their own diagnosis of cancer. Despite the fact all the respondents in my study were aware of developments in the medical management of cancer and that their prospects of survival were likely to be greater than they would have been even a decade ago, the fear generated by the memory of the short lives and pain and suffering of others remained influential in the way in which the news of their own cancer diagnosis was received by the respondents and more particularly their older relatives.

'Getting it Right' – in the absence of a script

The issue of whether or not (or how or what) to tell young children that a parent had cancer was difficult terrain for some respondents and was handled differently by individual respondents, ranging from Dean, who did not think that they should be told, to Faye, whose children were playing upstairs when I attended her house to interview her and who had been involved in an age-appropriate way from the early stages of her illness. There is a sense in which the respondents felt influenced by the need to 'do the right thing' but they could not always carry this through, for example, Dean has an awareness that popular culture would suggest that it is necessary and right to involve children but for him this would have been anathema. It is interesting to observe how far the respondents felt able to challenge societal 'norms' or how far they felt constrained by them. The fact is that there are very few norms in the context of cancer survivorship, as it is a fairly recent and unexplored phenomenon (Little et al, 2002).

The Survivorship Journey Revisited

The experience of survivorship being compared metaphorically to a 'journey' is common in many cancer narratives (Breaden, 1997, p982), and substantiates my earlier decision to organise the emerging themes into such an order. However, Breaden, in common with the majority of respondents in my study, found that this journey was "anything but linear. It was a journey that had unlit alley ways and dead end streets...There was no path *to* survival as this would imply an end to the journey. Each of the ...[respondents] were already surviving and would continue to do so for as long as each one of them lived. They did not have to wait for a specified end-point to be considered a survivor" (ibid, 1007, p 982).

There is a very real sense for some of being given a 'second chance', a form of re-incarnation, of experiencing life in a new way, of being a 'nicer' person (Robert), more in tune with oneself and less willing to succumb to the stresses and demands of everyday life (Susie, Jean, Kate and Bill) and there is the opportunity to 'live' as opposed to merely exist or survive (David and Faye). Some have deliberately and

consciously created a new life for themselves, in terms of changing career or adopting a healthier lifestyle, with the possibility of forming new relationships with their re-constructed identities. Some have carried on much as before, but with a renewed sense of purpose and meaning. Some, however, have not conformed to this typology, and have not noted any significant changes brought about by their experience. Thus, for some, the theory that the experience of cancer can create biographical disruption (see Chapter One) holds true, whereas others (a minority) may experience biographical flow or continuity, albeit with a temporary interruption.

It must be noted that this group of people, the respondents in my study, are relatively long-term survivors and thus their recollections must be seen in that light – cancer came to them at a point in their lives when they had the opportunity to be thoughtful, reflective and articulate about the experience. These individuals have confronted their own mortality and have not been defeated, but they have not come through the experience unscathed, and there is for some the nagging fear that the cancer may return, which puts some at least in the state of liminality. Those who have seen their experience of cancer as overwhelmingly positive and life-changing demonstrate aspects of the ‘survivorship’ status identified in Part One, but choose not to identify themselves with the term, preferring instead (if they wish to be defined at all) as saying that they are ‘living with and beyond cancer’.

It is significant to note that many respondents recognised that the positive lifestyle changes they had made since the cancer were not necessarily long-lasting, for example, the restricted diet they had assumed or the way of ‘living in the present’ and not thinking or worrying about the future. However, a number of respondents were able to say “I actually think it was one of the best things that could have happened to me” (Faye) “I have done a lot of things...but the route of them was the cancer” (David), “cancer is an emotional journey but has helped me to live my life in a more honest way...cancer has been one of the most positive things that has ever happened to me. It’s been an incredible journey and has enriched my life in ways I would never have thought possible”.

For many of the respondents, the sense of joy at still being alive seems to have outweighed other difficulties, for example, managing new relationships or the pain of treatment and subsequent after-effects, and this is borne out by Dee's exclamation part way through her interview: 'but still I am alive!' Dee had previously internalised society's view of cancer as a death sentence (Halstead and Fernsler, 1994, p 94) but had revised her opinion in the light of her own and others' continued existence. The sense of reincarnation, of being spared to have a second chance at life is corroborated in Sekse et al's research with women five years after having been treated for gynaecological cancer: "Gratitude for being alive was a strong issue, despite side effects and other problems following cancer treatment. The women felt they had been granted life as a gift for the second time" (Sekse et al, 2009, p 291). However, according to Breaden (1997, p 982) the expression of feeling 'lucky to be alive', which she also found as a recurring theme in her study of cancer survivors, could also become a burden to those who had survived cancer, as they may feel unable to express feelings of uncertainty and fear lest they be somehow labelled as ungrateful or demanding.

The feeling of needing to live in the present and of reduced anxiety over trivial matters was also a common theme in my interviews. Again, Sekse et al found that many of their respondents' basic values had changed as a result of their cancer experience: "Joy for life itself and being present in their lives became important, followed by a greater stability of mood, a more positive approach to life and the ability to distinguish more clearly between important and less important matters" (Sekse, 2009, p 291). Nevertheless the uncertainty associated with cancer survival would seem to be ever-present, in the accounts of my respondents and also those in other research studies – as Vachon has so powerfully described it, the sense of "‘Waiting for the other shoe to drop’ – the fear of cancer returning" (Vachon, 2001, p 281, cited in Doyle and Kelly, 2005, p 149)

The Need for a Holistic Approach to Care after Cancer

The number of respondents who had some previous knowledge of the healthcare system from a professional perspective is also noteworthy in how they brought this

experience to bear on their own interactions with the professionals responsible for their care. For example, Jean was able objectively to assess the medical consultant's communication skills in his delivery of the diagnosis and in assessing how much information she really wanted, and Margaret felt that her experience as a patient for the first time in her career as a cancer nurse had enhanced her ability to empathise with patients. The instructive nature of the experience of cancer is significant here, as Sekse et al (2009, p 293) comment: "The medical focus on cancer was important, but not sufficient, in handling...[individual respondents'] everyday lives and coming to terms with themselves after cancer."

What is also of significance in the accounts of my respondents are their individual encounters with the medical profession, the 'handling' of individuals by the professional world, and how well the character and style of each respondent equips them for the next phase – the encounter with themselves and their relationships with others. The frequency with which 'bad news' seems to have been broken in a brusque and unhelpful manner does not necessarily determine that the journey of the individual will be a negative one. The ability to 'survive', whilst acknowledging the respondents' very definite contesting of that term, seems to depend more on the resilience of the individual and the individual strategies they adopted to manage their illness and treatment, and again, not necessarily on the support they received (Scott-Davies, 2004). Vanistendael (2007, pp126-7) places the concept of resilience within the discourse of spirituality, recognising the need to find meaning in adverse life events (as discussed earlier, p 114- 115) to be a key element of both spirituality and resilience, embracing as it does the concepts of hope (although not necessarily in the hope of cure) and of forgiveness of the past. Holloway and Moss (2010) also see resilience as a "spiritual strength", stating that "a world-view that is able to offer some sense of meaning and understanding for what has happened, and to place it in a wider and coherent context... (p 88) can play a significant role in developing our resilience and enhancing our strengths and capacity to deal with adversity" (p 109).

However, the ability of respondents to recall minute details of how the news was broken and the poor communication of medical staff do point to the need for further training of professionals in this area, both at the time of diagnosis and into survivorship care.

The fact that some respondents chose to make recommendations for the development of services for people living with cancer, or were instrumental in developing services and policy themselves on a local and national level is evidence of the fact that they were motivated to do so from their own experience and a desire to make improvements for the growing number of people who will come in their wake.

In my final chapter, I will highlight the lessons I have learnt from this research and some of the changes it has already made to the policy and practice in this field, particularly in relation to the actual and potential role of social work with those living with and beyond cancer.

PART THREE

**INFORMING POLICY
AND PRACTICE**

Informing Policy and Practice

“A few decades ago, cancer illness was a topic shrouded in social silence. Today it is explored in television drama and documentaries, in interviews on radio and in print, and in theatre productions. The now familiar stories of accumulating suspicion, the shock of diagnosis and the ordeal of treatment...feature in written literatures from sociology to self-help...In short, stories of cancer illness have found a place in our culture. ...The emergence of this discourse means that those who become ill with cancer can expect some degree of acceptance and understanding...the same cannot be said, however, of those who *survive* cancer. Despite the interest that is often generated by stories of survival...there still remain unresolved tensions for those who have lived beyond the acute phase of ‘extreme experience’” (Frank, 1995, in Little et al, 2002).

Thus it would seem that it is not enough to have faced one’s own mortality and to have survived, to have ‘beaten’ cancer – the public perception of the disease still has associations of death and destruction and services designed to ‘help’ people with cancer have until recently been focussed very much on End – of – Life Care, without recognising the experience of those who are living with cancer as a long term condition. According to Doyle and Kelly (2005, p 148) “It is important to emphasise that cancer survival and rehabilitation are not simply theoretical concerns. They are realities for those who, increasingly, do survive a diagnosis of cancer.”

The message needs to be broadcast that the experience of cancer can be a time of personal growth and positive change; indeed, “Cancer patients, clinicians, families and friends should know that for most people cancer is not an entirely negative experience. The experience may lead to a deeper, richer and a more fulfilling life” (Foley et al, 2005, p 255)

In 2007, the NHS Cancer Reform Strategy for England in 2007 identified a need to improve the support provided to survivors of cancer. Following publication of this policy, the National Cancer Survivorship Initiative (NCSI) was set up under the auspices of NHS Improvement and Macmillan Cancer Support, to identify ways of further improving and developing the health, wellbeing and care for survivors of

cancer. Seven workstreams have been established and these focus on the following topics:

- 1) Assessment, care planning and immediate post treatment approaches to care
- 2) Managing active and advanced disease
- 3) Late effects
- 4) Children and young people
- 5) Self-care and management
- 6) Work and Finance
- 7) Research

The role of the Research Workstream is to identify and prioritise the most important unanswered questions so that research can be commissioned in the future to answer these. As a result the two National Cancer Research Institute-funded national supportive and palliative research collaborative, COMPASS and CECo, have been commissioned to undertake a rapid and comprehensive review of existing research evidence and consult with research organisations, charities and statutory organisations with an interest in survivorship research.

CECo, the Cancer Experiences Research Collaborative, is a partnership organisation between researchers and user representatives (Bailey et al, 2006). In the course of my research for this thesis I became a member of the Cancer Experiences Collaborative, and my research findings have been submitted as part of the national consultation exercise. In the documentation accompanying this exercise I have noticed a shift from the use of the word 'cancer survivor' to 'people living with and beyond cancer' which I find immediately encouraging as, as my research has shown, the term 'cancer survivor' remains contested and is seemingly not 'owned' by the very people whose experience it purports to describe.

In view of the dearth of other studies in this field, and the limitations of my study, I concur with Foster et al, as follows: "Research is needed to determine the long-term psycho-social implications of survival for people in under-represented groups such as ethnic minorities and those with rarer cancer types. Further research is needed to enable the effective support of those experiencing problems in the long-term when formal services may not be readily available as well as exploring the positive aspects

of long-term survival. Research will need to continue to monitor the long-term consequences of cancer survival. It is imperative that we are able to identify long-term difficulties and develop effective approaches to help people manage them, including support to self-manage such problems” (Foster et al, 2009, p245).

“There is no universal approach to cancer survivorship. Each cancer is treated differently and grows differently, and each patient has his or her own unique level of health and wellness. Our approach to long-term survivors must encourage wellness and constant vigilance, but consideration must be given to the experience, meaning and impact on the individual and family. Survival is not a singular aspect of one’s life, but rather an accumulation of physical, psychological, sexual, social and spiritual responses to changes that have evolved from the cancer diagnosis and its treatment. Therefore, long-term follow-up must be planned with an individual, family, community, societal and world perspective. To do this, we must know and appreciate the past, keep the history alive, and base our practice both on the patient’s past treatment and today’s health [and social] care advances” (Pelusi, 2001, p266).

Although I have identified common themes from the stories of my respondents, as Pelusi suggests, each person has their own individual story to tell of living with and beyond cancer. The route each person takes through cancer survivorship will be different for everyone and will require an individualised response from service providers, both health and social care.

According to Sekse et al (2009, p 297) “To improve the care for these patients, more attention should be given to psycho-social aspects, improved information and guidance about bodily changes and expected complications. Follow-up programmes should also take seriously the uncertainty...with which the wo[men] had to live. We suggest an additional follow-up that does not focus on medical examinations and tests, but rather on the individual patient and her specific needs, aimed at promoting a sense of control and empowerment.” As we saw in the Literature Review, *The Roles and Responsibilities of Social Work to People Living with Cancer*, social work, with its emphasis on psychosocial holistic care, is well-placed to meet the needs of those who are living with cancer, which, as we have seen from the previous

chapter, *Interpreting the Findings*, are beyond the reach of a solely medical model of care.

The National Cancer Survivorship Initiative has determined that there is a need for support for people who are living with and beyond cancer, but that there should be different levels of care dependent on assessment of need (Torjesen, 2011). Patients will follow a particular pathway based on 'risk-stratified care' (see Appendix 4) whereby patients will be channelled towards the most appropriate pathway according to their disease, treatment effects and individual circumstances.

In conjunction with this, the National End of Life Care Strategy, published in July 2008 and supported by the National End of Life Care programme, appointed social care leads in 2009-10, a Social Care Advisory Group was convened in March 2010 and in July 2010 the Social Care Framework, *Supporting People to Live and Die Well*, was published, establishing the importance of social care in end-of-life care service policy and practice. This has implications for social work interventions into survivorship, as the skills described in Chapter One that were so valued by service users of palliative care social work are eminently transferable to the survivorship context.

This does also represent a challenge to social work and particularly social work education as, as Holloway noted in her recent presentation at the JSWEC conference, July 2011, social work with people who are dying and bereaved is not rising to the challenge of death in contemporary society, and very few Schools of Social Work are emphasising the specialism in their teaching and training programmes.

However, there are opportunities in the field for social workers to be part of the multi-disciplinary teams working with the growing number of cancer survivors outwith the statutory sector. Macmillan Cancer Relief have piloted Health and Wellbeing Clinics in 15 areas across the UK, to "ease the transition into survivorship – recognising that many will have to live the rest of their life with the knowledge that they have had cancer and dealing with the practical effects it has had on them and those around them" (Moore, 2011, p 4). These clinics have been held in

a variety of settings, for example, football clubs specifically to attract men, and are often called ‘events’ or ‘sessions’ to distance them in the public mind from a medical model of clinical care. The informal multi-disciplinary approach of these events would seem to accord well with the tenets of social work, to offer psychosocial support to meet the kind of needs identified by respondents in my study.

Another trial is taking place at the Marie Curie Hospice in Hampstead of the efficacy of referral of cancer survivors to hospice day care. This hospice has for a number of years worked to a model of rehabilitation for its service users (Tookman, and Eades, 2010), and the social workers based there are used to working with the needs of people who are living with cancer and experiencing similar issues to those identified in my study (Eades, personal communication, July 2011).

I see both these developments as opportunities to promote the findings of my research, which has highlighted the many complexities, and both the positive and negative aspects of living with cancer in Western society. I hope it will encourage policymakers to reflect on the issues which my research has raised, namely that the experience of living with cancer is poorly understood in society and that the journey from diagnosis to ‘survivorship’ is fraught with uncertainty and fear, but that it can also be a life-changing experience for those concerned. There are many lessons to be learned, for example, about communication of the diagnosis and what support is relevant and appropriate to people who are ‘living with and beyond cancer’, but essentially there needs to be a recognition that it is an individual experience that needs to be managed sensitively by health and social care professionals alike.

APPENDICES

- APPENDIX 1: Key to Participants
- APPENDIX 2: Information for Participants
- APPENDIX 3: My Personal Research Journey
- APPENDIX 4: Risk Stratified Pathways

Appendix 1

Key to Participants

Brenda, aged 58, diagnosed with cancer of the ovary, white British female, single, no children, trained as a librarian (retired on ill health grounds)

Beth, aged 75, diagnosed with cancer of the breast, white British female, widow, with adult children, trained as a secretary (retired)

Bill, aged 55, diagnosed with cancer of the oesophagus, white Scottish male, now living in England. Separated, no children (retired on ill health grounds)

Dean, aged 38, diagnosed with brain tumour, white British male, married with young children. Works as a manager in a factory..

David, aged 57, diagnosed with cancer of the throat, white Scottish male, now living in England. Married with adult children, trained as a drama teacher, now works in crime prevention.

Dee, aged 56, diagnosed with cancer of the breast, white English female, separated, one child. Previously an attendant in a petrol station, now works as a beautician.

Faye, aged 42, diagnosed with cancer of the breast, white English female. Married with two young children, trained as a physiotherapist, not currently working.

Fiona, aged 76, diagnosed with cancer of the spine, white English female, trained and worked as a pharmaceutical dispenser before marriage and childrearing. Divorced, with four adult children, three living, one with advanced multiple sclerosis, one deceased

Gwen, aged mid 50s, diagnosed with cancer of the breast, white English female, trained as a teacher, now co-runs a theatre company and young people's service/counselling service for women with cancer. Married with adult children

Jean, aged 65, diagnosed with cancer of the bladder, white English female, trained as a youth worker/counsellor. Divorced, two adult children, retired.

Jo, aged mid50s, diagnosed with cancer of the breast, white English female, trained as a teacher, now co-runs a theatre company. Married with adult children.

Kate, aged 54, diagnosed with cancer of the cervix, white English female, lives with partner, no children, trained as a skater/masseuse, now works in tourist information service.

Lisa, aged 49, single, diagnosed with cancer of the breast, white Welsh female, trained as a social worker, still practising.

Margaret, aged 75, diagnosed with cancer of the breast, white English female, trained as a nurse, now facilitates cancer patients' support group. Widowed, married again, three adult children (two living with cancer).

Mo, aged 42, diagnosed with cancer of the breast, white English female, trained as a statistician, still working in this profession. Married with two teenage children and a stepdaughter in her twenties.

Robert, aged 57, diagnosed with cancer of the blood, dual heritage (Greek/English), trained as a Social Worker, now working part-time in Social Work Education. Recently separated from wife.

Susie, aged 70, diagnosed with cancer of the breast, white English female, trained as a teacher, now retired. One married daughter.

Teresa, aged 56, diagnosed with cancer of the breast, white English female, trained as an administrator, still working. Married with two teenage children.

Appendix 2

INFORMATION SHEET FOR PARTICIPANTS

Study Title

‘An exploration of individual experiences and reflections on living with cancer’

Thank you for agreeing to take part in this study. Below I have set out the aims of the research, the way in which you will be involved and some considerations on ethics and confidentiality. I hope you will find this information helpful, but please feel free to ask me for further clarification on any part of the study or your involvement in it.

Purpose of the Research

My research topic derives from nine years of practice as a Social Worker in a community hospice in Nottingham, during which time I encountered a great variety of individual reactions to the diagnosis of a life-threatening illness, and had the opportunity to observe at first hand the different ways in which individuals approached this phase of their lives. In my reading around the subject I have found that research in this area has concentrated in the main on evaluating service provision, on the control of pain and symptoms and not so much on the experiences of patients themselves. I am keen to redress the balance and am therefore conducting one-to-one interviews with a number of individuals who have been diagnosed with cancer, to explore what it is like to be living with cancer, with the hope that the study will contribute towards the body of professional and public knowledge about this experience and to inform policy and practice in this area.

This study forms part of my doctoral research at the University of East Anglia. My supervisor is Professor David Howe.

Process

Our interview will take approximately one and a half to two hours and will be audiotaped so that it can be transcribed for the purposes of analysis. It will be semi-structured, in that I will ask you questions which will prompt you to tell your own story about your experiences of being diagnosed and subsequently living with cancer.

Protocol

Approval for this study has been gained from the University of East Anglia Social Work Research Ethics Committee.

Having volunteered to be interviewed for this study, and having been given a verbal and written explanation of the purpose and process of the research, you will be asked to sign a consent form.

There should be no risk or harm to you. However, sometimes telling personal stories can be upsetting. You will not be asked to talk about anything that you do not want to and if you do find any aspects of the interview upsetting then I will stop the interview and the tape recording, at which point we can either recommence when you are ready or we can terminate the interview, if you so wish. I will endeavour to provide any assistance and support you may need should you become distressed.

You will, however, have the right to withdraw from the study at any time, without having to give any reason.

Your anonymity will be maintained throughout the study.

The issue of confidentiality will be discussed with you at the beginning of the interview. It is important to state that all information given during the course of the interview will be treated confidentially, with the exception of any information which may represent a risk to the safety of yourself or others, in which case I would be duty bound to pass this information on.

All written or recorded data will be kept in locked storage and will only be used as part of this current research project and any publications arising from the project. All audio tape recordings will be erased once the study is completed. You may request a copy of the transcription of your interview, if you wish.

Thank you again for your help with this study

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Appendix 3

MY PERSONAL RESEARCH JOURNEY

During the course of my research, which has extended over nine years, with periods of intercalation, I have had my own experiences of loss and change. I have lost friends through illness and death, including death from cancer, and my own father has been diagnosed with cancer. I have changed jobs, both by choice and otherwise, relationships of intimacy have been initiated and ended, and I have learnt a great deal about myself and my ability to cope in the face of changing circumstances.

Throughout this time, I continued to interview people who had been diagnosed with and were living with cancer. The experiences of these people have taught me more than I could ever have known from my previous work in palliative care of what it is really like to be living in the state of liminality that the diagnosis brings, and have enhanced my compassion and empathy for those who are undergoing change and disruption in their lives, and who have had the courage and confidence to share this experience.

I trust that I have done justice to these accounts and that the richness of the experience that they contain will serve to enlighten not only those who are yet to be diagnosed, but also those who are charged with developing policy and practice in this increasingly significant area.

Appendix 4

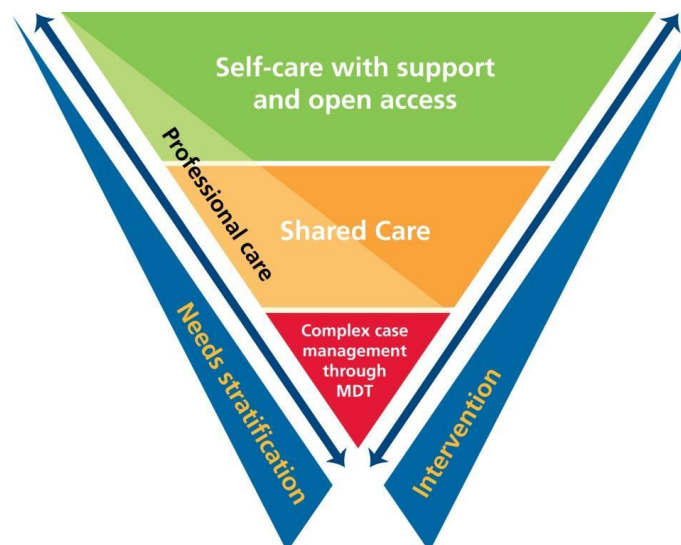
Risk Stratification

Risk stratified means that the clinical team and the person living with cancer make a decision about the best form of aftercare based on their knowledge of the disease, (what type of cancer and what is likely to happen next), the treatment (what the effects or consequences may be both in the short term and long term) and the person (whether they have other illnesses or conditions, and how much support that they feel they need). The three forms of aftercare are:

- Supported Self Management – where patients are given the information about self management support programmes or other types of available support, the signs and symptoms to look out for and who to contact if they notice any, what scheduled tests they may need such as annual mammograms, and how they get in touch with professionals if they have any concerns.
- Shared Care – where patients continue to have face to face, phone or email contact with professionals as part of continuing follow up.
- Complex Case Management – where patients are given intensive support to manage their cancer and/or other conditions.

The diagram below illustrates the risk stratification process. Cancer patients will be treated according to which approach is most suitable, and the level of professional care (illustrated down the left hand side of the triangle) will vary accordingly.

Cancer survivors may move between these different options according to how their cancer and its treatment progresses and whether they are more able to manage their disease, or whether they need more help. The proportion of people in each option will vary depending on the tumour type.



<http://www.ncsi.org.uk/what-we-are-doing/risk-stratified-pathways-of-care/risk-stratification/>

Last updated Feb 21st 2011

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