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Living with cancer : Living with dying: the individual's experience

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Living with Cancer,

Living with Dying:

The Individual's Experience

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Abstract

This thesis explores the experience of living with cancer and a terminal prognosis from the dying individual's perspective. It is based on qualitative sociological research. My study group comprised nineteen hospice patients, eighteen women and one man, aged 27 to 67, all of whom had been diagnosed with cancer. Thirty focused interviews were conducted; each respondents was interviewed at least once with a sub-group being interviewed a second or third time dependent upon symptoms, willingness to participate again and the need to explore issues further. My thesis is a sociological account of respondents' views and experiences, its focus is the management and negotiation of dying and death at an individual level. A central tenet of my thesis is how self-identity is constructed and negotiated in different social encounters, in both the public and the private sphere. With reference to the public sphere I consider respondents' experiences of communicating with health professionals, and the difficulties they encountered. Within this discussion I look at how respondents constructed understandings of their illness within the context of their own biographies. I also discuss individuals' experiences of treatment, and the choices they made about this. In addition, I examine respondents' hopes and fears for their own deaths, and I suggest the notion of a 'good enough' death may be useful in interpreting their views. Respondents perceived they had a spoiled identity as a result of their cancer and dying status. As a result they spent a great deal of time and effort engaging in emotional work, in order to reassert their more valued roles. Much has been written about the emotional work of paid and unpaid carers, here I suggest attention must also be given to the work of dying individuals themselves. However, I do not conceive of this emotional work as selfless, rather I suggest such work has benefits for individuals themselves. Emotional work enabled them to reaffirm or renegotiate more valued self-identities while alive, but in addition, I suggest that it also meant that respondents were able to contribute towards their own 'disembodied' after-death identities.

Contents

Introduction

This thesis explores the experience of living with cancer and a terminal prognosis from the dying individual's perspective. Its focus is the management and negotiation of dying and death at an individual level. Although it is important to understand how wider society and health care institutions and their staff deal with dying and death, it is not the purpose of this discussion to explore these views in any significant depth. My study group comprised eighteen women and one man, aged between 27 and 67, all of whom had been diagnosed with cancer, and had been referred to a hospice. During the course of my fieldwork I conducted thirty qualitative focused interviews; each respondents was interviewed at least once with a sub-group being interviewed a second or third time dependent upon their symptoms, willingness to participate again and the need to explore issues further. My thesis is a sociological account of respondents' views and experiences. I hope what follows does justice to them.

Although this is a sociological piece of work I hope that the contents of my discussion will be of interest to a wider audience, and not solely an academic one. Sociology, I believe should not be regarded purely in terms of being an academic discipline, rather it has a role to play in facilitating change both through exposing short-comings in existing practice and challenging taken for granted assumptions.

> The practical impact of the social sciences is both profound and inescapable. Modern societies, together with the organizations that compose and straddle them, are like learning machines, imbibing information in order to regularise their mastery of themselves..... Only societies reflexively capable of modifying their institutions in the face of accelerated social change will be able to confront the future with any confidence. Sociology is the prime medium of such reflexivity. (Giddens,1987,21)

I hope that my work will be accessible to academics, health professionals and those people generally interested in the care and experiences of the dying, because I believe that my respondents' accounts raise a number of important theoretical and empirical issues.

The sociology of dying and death

In 1958 Faunce and Fulton wrote a paper entitled 'The sociology of death: a neglected area of research.' They argue that:

> ......this neglect may be, at least in part, a reflection of a general reluctance in our society to acknowledge the presence and inevitability of death. (1958,206)

In 1993 Walter also argued that in the area of dying, death and bereavement British sociology had been particularly quiet, with the exception of medical sociology. In 1998 as I complete this thesis it seems that sociological, and other social science, interest in this area has increased dramatically. In particular, in the last few years, there has been an explosion in the amount of published material related to dying and death (e.g. Cline,1995; Jupp & Howarth,1996; Young & Cullen,1996; Field et al,1997). Further in 1996 the journal Mortality was launched "to promote the study of death as a medium for the publication of research and the stimulation of debate within and across disciplinary boundaries;" dying and death it seems are no longer 'neglected areas of research'.

It was during the 1960s that some of the first observational research in this area was conducted in the United States in general hospitals, concentrating primarily on staff-patient interaction (e.g. Glaser & Strauss, 1965,1968; Sudnow,1967). Since then other work has been undertaken within Britain in both hospitals (e.g. Knight & Field,1981; Cannon,1989; May,1990,1993) and hospices (e.g. Seale,1989; Johnson et al,1990; Mazer,1993; Copp,1996). While much of this research has concentrated primarily on the organisation of care for the dying, and staff-patient interaction, other research has looked at the attitudes of relatives and lay carers towards the care received by their loved ones (e.g. Addington-Hall et al,1991; Field et al,1992; Sykes et al,1992). Alternatively other social science research has considered the experience of bereavement (e.g. Littlewood,1992,1993; Dawson & Riches,1996,1997). However, research about the dying themselves and their experiences has historically been less prevalent. Perhaps, Field et al go some way to explaining this apparent neglect:

> There is an understandable reluctance to subject those who are terminally ill, who may be weak and nearing death, to questionnaires and interviews. Yet, if knowledge

about this group of people is to be increased and the care they experience improved, information and opinions must be gathered. (1995,45)

Despite these concerns some research has been conducted with dying people (e.g. Cannon,1989; Kellehear,1990; McLean,1993; Young & Cullen,1996; Young & Lee,1997). Each of these studies has taken a different approach. For example, Kellehear's quantitative work (1990) provides a comprehensive overview of the experiences of the dying, however, its scope does not permit the exploration of these experiences in any depth. By contrast, McLean's (1993) work documents the conversations she had with cancer patients, however, she does not provide any substantive analysis of her data. More recently in their book "The Good Death", Young and Cullen (1996) provide a detailed discussion of the qualitative research they conducted with a group of dying people and their loved ones in the last year of life. They present an account of the experiences of their respondents at this time, and use the powerful, and often emotive, words of those they spoke to support their work. Although other research has been conducted with dying people, I believe there is still a scope to develop further insights and understandings of the experiences of those living with a terminal illness. In my own research I focused solely on the perspective of the dying individual. Through the use of qualitative methods, I sought to provide in-depth detailed analysis of their views at this time, and thus contribute to existing sociological knowledge and debate about dying and death.

Dying, death and the role of the hospice movement

In this section it is useful to consider the ways in which experiences of dying and death have changed over time. Further, as all my respondents had been referred to a hospice for one of its services, it is also necessary to briefly examine changes within the hospice movement. Changes in the demographic structure in Britain have meant that people are now living longer. For example, a male born in 1997 has an estimated life expectancy of 74, and a female one of 80 years (Office of National Statistics,1997). Such changes in life expectancy have clearly had an impact on our expectations and experiences of death.

> In our society as the concentration of death among the elderly has become firmly
> established and has come to be taken for granted, so the death of the young has come
> to be almost unthinkable as part of the ordinary course of events.(Mulkay,1993,46)

Death is something associated with the aged in our society (Blauner,1966). This has not been the case in the past, for example, during the 19th Century the deaths of children were commonplace. Indeed it is only relatively recently that a more sympathetic attitude has been adopted towards parents whose child dies, because this is now perceived as being something out of the ordinary (Jupp,1997). Further, the actual nature of dying itself has changed

> Dying is not often the tragic striking-down that it was; it is more like the end of a
> slow process of running-down, more like a slow collapse. (Thomas,1980,3)

Historically death was likely to be caused by infectious acute illness; today, death is no longer sudden, but often the culmination of a long protracted chronic illness.

In the past dying and death were more visible, people died younger, within the home, and the family tended to their needs both while alive and after death. Increased longevity, changes in the family structure and increased social mobility has meant that often families no longer live in the same geographical location. As a result of this, in older age people are more likely to find themselves living alone, away from relatives, and consequently they are more likely to die away from home, cared for by professionals. In addition to dying and death being managed by the family, in previous centuries in Britain Christianity was also particularly influential, giving people's lives structure and meaning; informing their beliefs about health, illness, life and death (Shanley,1982). Gradually religion lost much of its influence in people's lives, as medicine increased its credibility and influence; ultimately the human body became secularised from the Church to medicine. It is often assumed that advancement in medical knowledge resulted in improvements in general health, however:

> The study of the evolution of disease patterns provides evidence that during the last
> century doctors have affected epidemics no more profoundly than did priests during
> earlier times. (Illich,1976,15)

Many infectious diseases were actually on the decline before medicine intervened with vaccinations. Reductions in the prevalence of such diseases are more likely be attributable to

general improvements in public health measures, improved sanitation and diet, and better living and working conditions, rather than advancements in medicine (McKeown,1979). With regard to death:

> The paradox was that despite the much touted successes of modern medicine in pushing back the frontiers of death and in dramatically rescuing some individuals from death, for most terminally ill people it seemed to have little of value to offer. (Field,1994,60)

Despite advances in medical technology and knowledge death still remains the only certainty in our lives.

While increased longevity has clearly had an impact on an individual's personal contact with, and experience of, dying and death another important fact has been the changes which have occurred in the management of dying and death[1]. Today dying and death are generally overseen and managed by professionals.

> Hospital death is endemic......Death without medical presence becomes synonymous with romantic pigheadedness, privilege or disaster. (Illich,1976,100-1)

Although the majority of dying still takes place within the home environment (Field,1996; Ramirez et al,1998), the majority of deaths now occur within a hospital or other institutional environment attended by health professionals (OPCS,1992). Corpses are then removed, and attended to by undertakers.

> Never before in the history of humanity have the dying been removed so hygienically behind the scenes of social life; never before have human corpses been expedited so odourlessly and with such technical perfection from the deathbed to the grave. (Elias,1985,23)

The role of the family in attending to the dying and dead has been eroded. Even within more geographically isolated communities, previous commonplace traditional practices have been replaced by more mainstream service providers (Clark,1982). Today, through technology doctors

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[1] It is not the purpose of this thesis to examine in detail the historical changes which have occurred in either the management of dying and death, or public attitudes towards dying and death. Ariès (1974, 1981) provides a comprehensive historical review of changing attitudes and practices. Clark's (1982) study of Staithes also provides a detailed account of a small community's practices of managing dying and death. Similarly Adams (1993) research in Foleshill, Coventry presents an analysis of how working class communities dealt with death and the effects of the rise of professionals on these practices.

now have the power to keep people alive, or to 'allow' them to die (James & Field,1992). To die without any medical involvement is now the exception, bringing with it its own 'problems'.

> Any fatality occurring without medical treatment is liable to become a coroner's case. The encounter with a doctor becomes almost as inexorable as the encounter with death. (Illich,1976,198)

However, it is important to note Elias' (1985) cautionary comment, that we should neither romanticise death in previous times, nor presume it to have been inherently 'better' than the way we die today. He believes that the traditional image of being surrounded by people on one's deathbed, may be neither a positive nor rewarding experience for anybody involved. However, what would appear to be true of dying and death in contemporary Western society, is that:

> Life grows longer, death is further postponed. The sight of dying and dead people is no longer commonplace. It is easier in the normal course of life to forget death. (Elias,1985,8)

As all my respondents had been referred to a hospice it is useful to consider, albeit briefly, the history of both the hospice movement itself, and the rise of palliative medicine. Today hospices appear to have become synonymous in the public view with dying and death.

> In Britain hospice care is now an important part of the services provided to terminally ill people and their close intimates in terms of the provision of domiciliary care, out-patients clinic, day care and in-patient care; in terms of the education and training of health care personnel in terminal and palliative care; in terms of the wider impact hospice research has had on pain relief and in terms of the ideology of care which underpins these activities. (James & Field,1992,1368)

It is often assumed that the hospice movement is a relatively recent health care development, but they have been recorded as far back as AD. 475 in Syria (Campbell,1986). However, it is in the 19th Century and early 20th century that the forerunners of today's hospice movement can be detected.

> ...the origins of the contemporary movement may be traced to the foundation, by the Irish Sisters of Charity, of a hospice in Dublin....In 1900 the Irish Sisters of Charity opened St. Joseph's convent in London, and in 1902 they opened St. Joseph's hospice for poor people who were dying. (Littlewood,1992,15)

Dame Cicely Saunders worked at St. Joseph's during the 1950s, before founding St Christopher's hospice in 1967. The ethos that she developed for St. Christopher's, and which remains the

principle tenet of modern hospice care, involves an holistic approach addressing emotional, physical, spiritual and social needs. Saunders believed that concentrating purely on a dying patient's physical well-being was insufficient, rather what was required was a form of care addressing all patients' needs, as well as the needs of their families (Glover Halthon,1986).

The majority of hospice work load involves caring for terminally ill cancer patients, followed by patients with Motor Neurone Disease and HIV/AIDS (Eve *et al*, 1997). Cancer affects individuals of all ages, and it now accounts for the largest numbers of deaths in Britain (Cancer Research Campaign cited in Mayor,1998). All my respondents were aged 27-67 and had been diagnosed with some form of cancer. In the 25-65 age group cancer accounts for the largest number of deaths in women, and the second largest amount of deaths in men (after circulatory disease) (Office of National Statistics,1997). The fact that respondents had been referred to a hospice is perhaps not too surprising, when one considers that in 1990 it was estimated that 14% of all cancer deaths occurred within hospices (Addington-Hall & McCarthy,1995). However, as a group, they were less typical of hospice patients generally, because 65% of admissions to hospices are over the age of 65[2] (Eve *et al*, 1997).

One fundamental change in hospice care in recent years, and a source of considerable debate is the increased involvement of medical professionals in the multi-discipline hospice team.[3] In 1987 the Royal College of Physicians recognised palliative medicine as a sub-speciality of general medicine for the first time. Palliative medicine is concerned with 'active, progressive and far advanced illness'; its aim is to relieve suffering when cure is no longer possible (Doyle,1993). Biswas (1993) believes that mainstream medicine's acceptance of palliative medicine, has the potential to undermine the fundamental principles on which the hospice movement is based. She

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[2] Statistics for the period 1st April 1995 to 1st March 1996 provided by The Leicestershire Hospice, where my research was conducted, also reflect these national trends in referrals.

[3] The aim of this part of my discussion is to provide some background information about the ways in which hospice care has changed over the years. It is not my purpose to document in detail the debates about the rise of the palliative medicine which can be found in: James & Field,1992; Biswas,1993; Ahmedzai,1993,1994; Field,1994; Hockley,1997.

views the increasing number of full-time medical appointments with suspicion. She believes this to represent a significant break with the past, when, medical input in the multi-disciplinary team was often part-time. While acknowledging that relief of symptoms through palliation is important, Biswas fears that increasing technology and treatments may ultimately shift the emphasis away from death. She argues for a distinction to be made between palliative and terminal care.

> Palliation is the relief of symptoms, and the logical extension of this view is that death is a symptom, and with increased expertise in palliation techniques, death can be alleviated altogether. Terminal care on the other hand, acknowledges that death is a process, and not a symptom and, as the only certainty in life, can not be avoided. (Biswas,1993,135)

Field, like Biswas, also has concerns about the rise of palliative medicine:

> There has been substantial achievement and significant benefits from the medicalization of death, but also unnecessary suffering and psychological harm of patients and those close to them (1994,58)

Field (1994) highlights five concerns about the rise of palliative medicine: firstly there is a lack of clarity about both its extent and how it differs from other specialities; secondly, he, like Biswas, notes that there is a potential for an increased emphasis on palliative medicine to result in a shift away from terminal care; thirdly, he suggests there may be inappropriate use of medical technology; fourthly, an increase in the role of medical staff may be at the expense of other health workers; and finally, and perhaps most significantly, he argues that palliative medicine has the potential to shift the emphasis away from the notion of providing holistic care, which may further blur the distinction between hospice and other institutional care. The concentration of palliative medicine on cancer patients (predominantly) has other consequences. For example, what of the care of people dying of other causes? In addition, traditionally hospices have also cared for patients' families, what does palliative medicine have to offer to these people? (Field,1994)

In response to Biswas and Field, Ahmedzai (1993,1994) defends palliative medicine, and asserts that it does have an important role to play in the care of the terminally ill. 'Terminal care', he argues, is too blunt and confined to the last few days of life. He argues that palliative care may allow an earlier involvement with patients, before they are admitted to the hospice. This, he

asserts, may reduce patient distress because it is possible to begin communicating with them and their families earlier in their illness.

> As more of the difficult symptoms and syndromes of the terminal stages of life become potentially palliatable, will we see more examples of invasive and technological therapies being assimilated into previously low-tech hospice care? If so, does that process represent intrusive medicalization, or the rational application of a better understood and safer therapy to a wider pool of patients who may benefit? (Ahmedzai,1993,141)

Further, Ahmedzai (1994) argues that if the central premise of the hospice movement is to allow the individual to die with dignity, then the relief of physical pain is an important factor in ensuring that this goal is achieved - and therefore palliative medicine has an important role to play.

Although hospices are now firmly established as providers of specialist health care for the terminally ill, one should not assume that everyone welcomes the involvement of these specialist services in their care (Seale & Kelly,1997a; Corner & Dunlop,1997). Furthermore, the fact that hospices provide care predominantly for those with terminal cancer means that their approach is not always appropriate for those dying of other causes (Seale,1991a). It is also ironic that the success of the hospice movement in influencing the care of the dying, in particular emphasising the importance of 'open' communication with regard to dying and death, has actually meant that the care provided within hospices is no longer notably different to that of mainstream hospitals (Parkes & Parkes,1984; Seale,1989). James and Field (1992) develop this point further by arguing that hospice care has now become 'routinised'. They believe this to represent a fundamental threat to the holistic principles of hospice care, as the movement moves increasingly towards more mainstream medical practices. Finally, although the hospice movement has made a significant impact on the provision of terminal care, and there have indeed been changes generally in communication practices between staff and patients and their families, there still remains room for improvement (Addington Hall *et al*,1991; Seale,1991b; Sykes *et al*,1992; Addington-Hall & McCarthy,1995).

Thesis structure and contents

A central tenet of my thesis is how self-identity is constructed and negotiated in different social encounters; it is a guiding theme, both explicitly and implicitly, throughout my discussion. In my thesis I am aware of three important questions: Whose definition of respondents' identities is important? What role do professionals and loved ones play in its negotiation? How is self-identity at this time constructed and maintained? Throughout my thesis I use the phrase 'dying and death' despite the fact much of the literature in this area refers to 'death and dying'. My first objection to discussing 'death and dying' is that it seems illogical to talk about the event before the process which leads to it. However, more importantly, given that this thesis focuses on the experiences of living with the knowledge that one is dying, to talk about death and dying seems inappropriate because this phrase implies that the death is more important than the dying.

I feel it is also important to establish how I use the term 'dying' in my thesis. While we are all literally dying it is also true that for the majority of us the actual point at which we will die remains unknown. However, a terminal prognosis makes the end of life something which is now possible to locate within a particular period of time. Although individuals will still not know exactly when they will die, given changes in medical practice they are much more likely (particularly if they have a diagnosis of cancer) to be told that there are no more curative treatments available. When this is the case an individual's illness status changes from someone who is 'ill', that is recovery is possible, to that of someone who is 'terminally ill' and 'dying'. Individuals may or may not be aware of this change of status at the same time as medical staff, equally, they may choose not to acknowledge their awareness. Further, given the vagaries which occur during discussions between staff and patients, some individuals may not be aware that their treatment is now palliative. Although the majority of my respondents had been told that there was no other curative option available to them, it is important to note that during the interviews I conducted, not all individuals spoke directly about dying and death. However, like Abiven (1996)

I feel that even if individuals do not explicitly say that they know they are terminally ill, they are often aware.

The structure of my thesis has been formed by the experiences of respondents and I hope what follows reflects their thoughts, feelings and experiences as they described them to me. The fact that I wanted my work to be 'data centred' has meant that my discussion is concerned with both practical and theoretical health care and sociological issues. More specifically the data chapters address issues pertinent to the public and the private sphere - Chapters 4 and 5 are concerned with the public sphere, and Chapters 6 and 7 address issues related to the private sphere. This division I feel is inevitable given that an initial diagnosis of cancer, and a subsequent terminal prognosis, necessitates that a person will spend at least some time in medical encounters and institutions. It is clear, therefore, that individuals will reflect and comment on these experiences and to ignore what respondents said about this part of their lives would present a partial picture. However, the public domains of hospital wards and out-patient clinics were not the only environments in which respondents interacted with others, in fact, the majority of dying takes place within the private sphere of the home. In these settings respondents were not patients but mothers, brothers, daughters and friends, and it is their experiences of re-negotiating and managing these identities at this time which is central to my discussion in Chapters 6 and 7.

The aim of my first chapter is to explain and discuss some of the concepts which I draw upon later in the thesis. Within this chapter I consider some of the organisational tools which have been used to manage the care of the dying, and address their implications for patients themselves. I also look at what it may mean to be dying within contemporary British society, by considering attitudes towards the dying, and the subject of death generally. Finally in this chapter I introduce some concepts which are pertinent to my later discussion of the negotiation and management of a dying identity. Chapters 2 and 3 address the ethical, methodological and practical issues raised during my fieldwork. Chapter 2 documents the practicalities of the fieldwork process, and it is

here I provide some biographical information about each of my respondents; Chapter 3, alternatively, is concerned with the ethical and methodological implications and problems raised by conducting qualitative research of this nature. In the latter four chapters of my thesis I discuss the qualitative data which emerged from my fieldwork. Chapters 4 and 5, which concentrate on the public sphere, are concerned specifically with examining respondents' experiences of the care they received. In Chapter 4 I look at how respondents communicated with health professionals. I discuss their accounts of how they were told their initial diagnosis, and later prognosis, and their thoughts and feelings about this. In this chapter I also consider how respondents' understandings and interpretations of their cancer accorded with more pervasive biomedical explanations. In Chapter 5 I explore respondents' experiences and understandings of the treatment they received - surgery, chemotherapy, radiotherapy and morphine. In the final section of this chapter I also consider respondents' hopes and fears for their own deaths, and the implications this may have for health care. Chapters 6 and 7 relate to respondents' experiences in the private sphere. Chapter 6 begins by addressing the effects a diagnosis of cancer has on an individual, before moving on to consider the impact it has on personal relationships. It is in this chapter I discuss the extent to which living with cancer and dying damages an individual's self-identity. The last chapter of my thesis considers how respondents managed their cancer, and later dying, status. Here I am particularly interested in how individuals continued to negotiate interactions with others at this time and how they managed potentially difficult conversations; a central theme in this chapter is the role of respondents' 'emotional work'. Finally in my conclusion I reflect on, and reiterate, the central concerns raised in my thesis.

Chapter 1

Dying and Death - Organisational and personal challenges

This chapter provides an introduction to some of the concepts and debates which are discussed later in my thesis. I begin by considering some of the organisational dilemmas dying and death present for health professionals. Specifically I discuss how stage theories, awareness contexts, and the Good Death may facilitate the management of dying and death for staff, but may hold little meaning for patients themselves. The aim of my research was to explore the experiences of living with cancer and living with dying from the individual's perspective. In order to fully understand the context of these experiences it is important to address contemporary attitudes towards the dying and dead, as well as towards the subject of death. As part of this process I consider the extent to which death can be seen as a taboo in contemporary Britain. Throughout my thesis certain themes are apparent: issues of 'control', 'negotiation' and 'management' of different social encounters. Central to each of these is the notion of self-identity: how individuals perceived themselves, how they felt others perceived them, and how they sought to limit the effects of their dying on their social relationships. In this first chapter it is therefore also necessary to examine how individuals construct their self-identity, and also briefly to consider how a 'damaged' self-identity can be managed and re-negotiated.

'Stages' of dying

As noted earlier death has become increasingly institutionalised, this has meant that the process of dying is now commonly managed by health professionals. In order to facilitate this process staff have sought to define and label dying, thus imbuing it with some kind of 'structure' which can be followed, compared and checked to ensure that people are dying in an 'appropriate' way (e.g. Glaser & Strauss,1968; Kubler-Ross,1969). Other work has concentrated on patients' awareness of their diagnosis and prognosis (e.g. Glaser & Strauss,1965). More recently, discussions about the management of death have focused on the concept of the Good Death (e.g. McNamara *et*

al,1994,1995). These discussions share much in common, because they are all concerned to with an 'ideal' type of dying and death. While the concept of the Good Death is most pertinent to my own discussion, a consideration of the work of Kubler-Ross (1969) and Glaser and Strauss (1965,1968) provides useful insights into the notion of 'ideal' dying, where the ultimate goal is patients being aware and accepting of their dying status.

In this chapter I am more concerned with Glaser and Strauss' (1965) work on 'awareness contexts'. However, it is also important to note their later published work *Time for Dying*. In this, Glaser and Strauss (1968) illustrate how hospital staff sought to define and structure patients' dying by monitoring the patient's 'dying trajectory'. This is the medically perceived (rather than the actual) course of dying which takes place over a period of time; it is originally defined by staff and is crucial to both the organisation of work and 'sentiments'. Ultimately this process should end in the patient reaching 'open awareness'. The dying trajectory varies over time as professionals' knowledge of the patient changes. It has duration and shape, and can be graphed and monitored, important 'critical junctures' are identified to assist professionals in their management of the patient. This perceived trajectory ensures that medical staff are able to 'temporalize' every aspect of the hospital career of the dying patients. The dying trajectory allows staff to manage death effectively, even though this may be at the expense of disregarding patients' own definitions and understandings of their situation.

The most frequently cited 'stage theory' is the work of Elisabeth Kubler-Ross (1969). Kubler-Ross conducted interviews with dying people and identified five stages in the dying process: denial and isolation, anger, bargaining, depression and acceptance. In this work she states:

> It is not meant to be a textbook on how to manage dying patients, nor is it intended as a complete study of the psychology of the dying. (Kubler-Ross,1969, Preface)

Despite this statement, it would seem that it has been interpreted as such by some health professionals. There is a danger that by using the model prescriptively rather than descriptively

patient experiences will "become either reinterpreted or concretized to fit neatly into stages" (Charmaz,1980,153). When this occurs the Kubler-Ross stage theory becomes a :

> ....rigid set of rules that [proposes] what every person ought to be doing rather than a set of guidelines given for the intent of providing an aid to understanding what patients close to death experience. (Germain,1980,52)

Interpreting the model in this way, may mean that patients who do not follow this pre-defined pattern of dying will be viewed as 'deviant' (Kastenbaum,1975 cited in Littlewood,1993 & Kellehear,1990; Germain,1980). Kubler-Ross' work has been criticised on a number of grounds. For example, Charmaz (1980) questions its suitability for those individuals from lower socio-economic groups in the United States, who are likely to experience added stress because of additional financial expenses incurred because of their dying. She argues that Kubler-Ross' stage theory does not necessarily describe an individual's responses to dying, but rather reflects the social context of their dying within an alien institution. Further, Charmaz suggests that the social conditions of Kubler-Ross' sample - in the main hospitalised, many were also uninformed of how serious their condition was, and many described a strained relationship with staff - go some considerable way to explain the stages identified. In addition Kellehear (1990) criticises Kubler-Ross' work on methodological grounds because she fails to give any adequate account of her sample group in terms of age, gender, class and ethnicity.

A prescriptive interpretation of Kubler-Ross' model also leads to other problems. For example, patients may be labelled by a professional who only has fleeting contact with them. Despite this, the label is likely to endure, even though it may be an inappropriate description to use at another point in time. In particular the label 'denial' appears to be frequently used both by health professionals when describing patients and in academic literature (Kellehear & Fook,1989). Charmaz (1980) argues that 'denial' is often used to describe 'awkward' patients, who may be behaving in ways deemed 'inappropriate' by staff. Further, it may also be the case that 'denial' in some circumstances may merely reflect a patient's perception of a given situation (Kellehear & Fook,1989). For example, if doctors themselves do not talk about death, this may in fact be taken

as a cue from patients to do the same. 'Denial' it seems is generally assumed to be negative and undesirable. However, Smith (1993) argues that it can actually be positive because it may help the individual to cope with their prognosis; given this, to try to 'break down' a patient's 'denial' is neither always appropriate nor beneficial. As Kellehear and Fook (1989) note, 'denial' may also be seen in terms of Goffman's (1978) concept of 'role distance'. That is individuals who are dying do not deny this fact *per* se but wish to 'distance' themselves from certain aspects of the dying 'role' to show that they are not completely absorbed by this role:

> ....the individual is actually denying not the role but the virtual self that is implied in the role for all accepting performers. (Goffman,1978,108)

Interpreting events in rigid prescriptive stages does not account for a more fluid movement between 'acceptance' and 'denial', nor does it allow for the individual to feel both at any given time:

> Patients seem to know and want to know, yet they often talk as if they did not know and did not want to be reminded of what they have been told. (Weisman,1972,66)

> The balance between denial and acceptance changes like a kaleidoscope during fatal illness; old fragments constantly rearranged themselves into new patterns. (Weisman,1972,122)

Weisman refers to this state as 'middle knowledge'[1] which he sees being between open awareness and denial.

Why is it, given these criticisms, that Kubler-Ross' model has had such an impact on the care of the dying?

> The attraction of stage or phase types of analyses may well lie in their ability to represent the experiences of people who are dying and people who are bereaved in a culturally acceptable manner (i.e. as an experience which follows an ordered linear progression)....Paradoxically [this] presentation may only ever make sense to people who have not experienced bereavement, e.g., in all probability most young to middle-aged health care professionals in contemporary societies. Perhaps it is to this audience that such a presentation is addressed. (Littlewood,1993,73)

Such 'stages' of dying can, therefore, be viewed as organisational tools which give structure to the care of the dying by offering the possibility of a predictable course against which patients can

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[1] This is a term originally developed by Hackett & Weisman (1962)

be compared and monitored. While such 'stage theories' may help make the tasks of health professional easier, they may hold little meaning for dying patients and their families.

Dying and awareness

Although some understanding of the way dying and death is managed is useful to this discussion, what is of more relevance to my own work, particularly the discussion in Chapters 4 and 5 is the way in which patients receive information about their diagnosis and prognosis, and how this has changed over time. From the mid 19th century until the 1950s it became common practice to avoid revealing a terminal prognosis to a patient (Ariès,1981). Literature in this area suggests that now the majority of doctors prefer patients to be aware of their condition (Timmermans,1994), a trend which is supported by public opinion (Williams,1989).

Changes in the care and management of dying, in particular the influence of the hospice movement, have meant that today people are more likely to know that they are dying, and to know this for a longer period of time (Seale,1989; Seale & Cartwright,1994). It would seem therefore that the debate has now moved from one of 'whether' to disclose, to 'how' to disclose (Field,1989). Although it is more common for patients (particularly those diagnosed with cancer) to be told their prognosis (Seale & Cartwright,1994), and although my own research focuses on the experiences of terminally ill cancer patients, it should be noted that not all individuals who are dying receive the information they would like.

> The debate about telling patients their prognosis, to which the hospice movement has
> made such a significant contribution in the direction of open awareness, is based on
> the assumption of the cancer patient as a model. (Seale,1989,557)

Seale asserts that difficulties may arise when doctors are faced with a patient with a non-malignant disease, where the point of death may be less clear, perhaps interrupted by periods of improvement or hastened by acute episodes. Advances in medical technology have also meant that it has become more difficult to actually identify the point at which death is likely to occur (Field & James,1993). What information individuals receive about their condition also appears to

vary by age, with younger patients having their diagnosis and prognosis disclosed to them more often than elderly patients (May,1993). People dying with cancer are more likely to fit into this former category: they are likely to be younger and still have spouses and siblings alive. They are, therefore, more likely to have other people around them, and are consequently less likely to die alone (something generally regarded as being undesirable (Seale,1995b; Seale & Kelly,1997b)). Although dying patients with non-malignant diseases may not have access to the same amount of information as the dying cancer patient, it should not be assumed that all cancer patients know as much about their prognosis as their doctor. Part of this discrepancy may be due to the fact that sometimes doctors may be reluctant, or have difficulties admitting that a patient has reached the terminal stage of their illness (Davis *et al*,1996). In addition, the trend towards disclosure may also need to be viewed within a culturally specific context. For example, Porta *et al* (1997) note that in Mediterranean countries there is often resistance to telling cancer patients their diagnosis, because of the strong negative reactions associated with the disease.

Accepting that awareness of both diagnosis and prognosis is likely to vary considerably, it is still useful to examine previous research in this area. Such work serves to provide an historical perspective to my later discussion of the data, as well as highlighting the problems which have been, and may still be faced by the dying. The following discussion considers Glaser and Strauss' (1965) discussion of 'awareness contexts'. They conducted their research in two American hospitals and discovered that staff, in the main, preferred not to tell patients that they were dying, and further staff received very little training in communicating with dying patients. They suggest a hierarchy of knowledge existed: Doctor > Nurse > Patient. Doctors have ultimate control over the disclosure of a terminal prognosis; they may choose to tell nurses directly about the prognosis, or merely reveal enough information so that experienced nurses can draw conclusions from the information available. Patients are unlikely to be told directly of their condition, rather they gather information about their condition from clues given by doctors and nurses.

Glaser and Strauss explore patients' awareness of their conditions, and their management of this knowledge. They identify four 'Awareness Contexts': closed awareness, suspected awareness, mutual pretence awareness and open awareness. 'Closed awareness' refers to the situation which exists when patients are unaware of their condition, but staff are aware - the difficulty inherent in this situation is maintaining closed awareness with conscious sentient patients. Glaser and Strauss divide 'suspected awareness' into three different categories: firstly, 'closed suspicion', when patients are suspicious about their condition but the staff are unaware of this suspicion; secondly, when the staff are suspicious and wonder whether patients really know, but are choosing not to tell them, in this case the staff must be very careful to hide their own suspicion; and thirdly, when staff are certain of patients' suspicion, resulting in a situation of 'open suspicion'. 'Mutual pretense awareness' occurs when both staff and patients are aware of the terminal prognosis, but neither chooses to talk to the other about it. This can either develop into 'open awareness' (when both staff and patients are aware, and acknowledge it through their actions), or alternatively it may continue for a length of time making it more difficult for staff and family to sustain. Although 'open awareness' may appear to be the ideal, it does not necessarily mean that patients know everything. For example, individuals may be aware that they are going to die but may be unsure of when; medical staff, by contrast, may have more precise knowledge. In such a scenario, Glaser and Strauss argue, the patient is in closed awareness about the time of death, although as with the discovery of a terminal prognosis, this may change to suspicion awareness over time. It is likely that given current trends towards informing patients of their prognosis, this latter situation is probably more common.

This discussion of awareness is particularly pertinent in Chapter 4 when I consider respondents' accounts of their own experiences of learning both their initial diagnosis and subsequent prognosis. I make particular reference to Timmermans' (1994) work. Timmermans develops Glaser and Strauss' original awareness contexts theory to make it more relevant to current practices, by concentrating specifically upon the context of 'open awareness'. His paper shows

that even when individuals are fully informed of their condition it does not necessarily mean that the 'ideal' state of Glaser and Strauss' open awareness will exist. Timmermans suggests the context of open awareness should be subdivided thus: suspended open awareness, uncertain open awareness, and active open awareness. 'Suspended open awareness' is characterised by the patient, or family, ignoring information given to them by the doctor. 'Uncertain open awareness' is exhibited when the patient, or family, dismiss the bad parts of the information they have received, and dwell particularly on the positive aspects of what they have heard, and ignore those with more negative connotations. 'Active open awareness' (comparable with the original concept of open awareness advocated by Glaser and Strauss), occurs when the patient, or family, accept the news of their impending death, and begin to prepare for it. The crucial difference in Timmermans' analysis of awareness contexts is not how patients understand the information, but how they respond to it emotionally. It is not necessarily receiving more medical information given to them which leads to open-awareness, but rather the extent to which people listen, and make sense of what they are told. Although people may have been told about their diagnosis and prognosis, they may not necessarily either acknowledge this fact, or respond to it in a realistic manner. How patients and relatives cope emotionally with a terminal prognosis is, in Timmermans' view, crucial in determining the kind of open awareness achieved. Given that Timmermans asserts 'active open-awareness' is the ideal towards which health professionals now strive, and that they may feel they have 'failed' if the patient does not achieve this, it is important that they take individuals' emotional responses to their prognoses into consideration when communicating with patients and their families.

The Good Death

'Open awareness' is also closely linked to another concept frequently discussed in palliative care literature - the Good Death. Indeed it is argued that one of the central premises of the hospice is the notion of the Good Death (McNamara *et al*,1994). McNamara *et al* (1995) assert that hospice staff feel that providing effective symptom control, that is reducing a patient's pain as much as

possible, enables that individual to die with dignity. However, a Good Death is more than effective symptom control:

> The Good Death is....defined as 'good' if there is an awareness, acceptance and preparation for death. (McNamara *et al*,1995,223)

Weisman (1988) suggests that the hospice movement is concerned with achieving three main aims: firstly, appropriate death for patients; secondly, anticipatory grief work of survivors; and thirdly, maintenance of staff morale. 'Appropriate death', as Weisman terms it, may be seen to be a similar concept to the Good Death:

> An appropriate death has been defined as a death that one might choose, had one a choice. It means dying in the best possible way, not only retaining the vestiges of what made life important and valuable, but surviving with personal significance and self esteem, along with minimal distress and few intractable symptoms, as long as possible. (Weisman,1988,67)

Weisman outlines four factors which are necessary to achieving an appropriate death. Firstly, awareness: one must be aware that nothing else can be done, and then one must display acceptance of this fact (although he notes this may be difficult to achieve). Propriety must also be maintained, this involves allowing people to die in the way they want, providing this does not offend the customs and beliefs of the wider community. An appropriate death also involves restoring an individual's autonomy and preserving dignity as much as possible. Finally, timeliness - that is dying at an appropriate time - is also important to an appropriate death; sudden or lingering deaths, for example, may be detrimental to achieving this. Kellehear (1990) also describes five features of the Good Death, which can be viewed in conjunction with Weisman's criteria. Kellehear argues that not only is personal awareness necessary for a Good Death, but public awareness is also preferable. People need to make social adjustments and preparations with regard to personal relationships, as well as public preparations, such as writing a will and organising their own funeral. Generally, Kellehear notes, dying people are also expected to give up work, although this is not necessarily a formal requirement in achieving a Good Death. As with Parsons' (1991) model of the 'sick role'[2], the dying person is expected by the wider community to abstain from economic activity. The final criterion of the Good Death, Kellehear

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[2] Parsons' concept of the 'sick role' is discussed in more detail in Chapter 4

argues, is that the dying person needs to say informal and formal farewells to both staff and loved ones.

Many of the 'criteria' necessary for a Good Death are facilitated by the ethos of the hospice movement, which seeks to encourage people to 'come to terms with' their disease and 'prepare' for their death. Given the policy of open communication within hospices, it may be assumed that all patients should die a Good Death. However, McNamara *et al* (1994) discuss what they see to be challenges to the Good Death within the hospice movement. The first they highlight is what James and Field (1992) have referred to as the 'routinisation' of the hospice movement.

> Hospice and palliative care, and implicitly the Good Death model are, however, constantly threatened by the encroachment of mainstream medicine.....One doctor presented a series of case studies.......[they] illustrated how potentially 'good' deaths were made 'bad' by invasive and inappropriate investigations and treatments instigated within the mainstream medical establishment. (McNamara *et al*,1994,1505)

Aside from any debate about increasing medicalisation in hospice care, McNamara *et al* (1994) discuss how competing motivations between patients and staff within the hospice, may also make the Good Death difficult to achieve. An intrinsic part of the Good Death is the patient's awareness of their condition, and the open display of this awareness, but more importantly, an acceptance of this awareness. If patients do not accept the reality of their situation staff may begin to feel uncomfortable and then the situation may become problematic. Age may also be another important factor in influencing whether a patient achieves a Good Death or not. Blauner (1966) argues that older members of society may feel that they have had a full life, and before their death may have the opportunity to reflect upon their life and the contribution they have made to others' lives in a positive way. However, younger people may not feel accepting, they may well resent the fact that their life seems to have been unfairly curtailed; for these people, and others, the Good Death may be unrealistic and never achieved.[3]

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[3] I realise it is too simplistic to assume that all older people will be prepared to accept their death in this ideal way. However, as I discuss in more detail later in this chapter age is clearly an important factor when discussing dying and death.

Given the above, is the Good Death merely another concept which primarily holds meaning for staff? This would seem to be the case if one accepts the argument that death is often seen as 'failure' (Illich,1976), the notion of a Good Death may actually serve for those working with the dying to imbue their job with status.

> Hospice nurses actively work towards the Good Death and in doing so reverse the definition of death as bad or as a failure. (McNamara *et al*,1995,255)

Further, just as a prescriptive interpretation of Kubler-Ross' model may be potentially damaging to the patient, so Hart *et al* (1998) also argue that the ideology of the Good Death may too have become a form of social control of the dying, constraining and dictating their behaviour. It seems, therefore, that a tension may exist between the desire to achieve a Good Death and the founding aim to provide individualistic patient care (Payne *et al*,1996).

> Patient autonomy is compatible with the values associated with the Good Death, yet patient compliance is seen by nurses and other health professionals as necessary for good symptom control and for the efficient running of the organisation.....Non-compliance is problematic. (McNamara *et al*,1995,231)

McNamara *et al* (1994) suggest that the Good Death does indeed merely serve as an intellectual structure for health professionals.

> We always seem to be looking at the Good Death from the nurse's perspective rather than the patients....What are the patient's expectations.....we need to give people permission to make their own decisions (Quote from a hospice nurse).
> (McNamara *et al*,1994,1506)

The Good Death is of significant benefit to the organisation of the hospice, a bad death, alternatively, may be a drain on resources. The Good Death therefore though 'good' for staff morale may not necessarily benefit patients. Further, McNamara *et al* (1994) continue, it has become increasingly routinised within the hospice movement, with nurses asserting that the Good Death is the norm, rather than the exception. This may lead to sudden, or lingering deaths being viewed as problematic by nursing staff. Certainly it is well-documented how 'awkward', or non-compliant patients who do not come to terms with their condition present problems for staff (e.g. Glaser & Strauss,1965; Sudnow,1967; Field,1989; Mazer,1993). For example, such 'awkward' patients may find that they are actively avoided by staff. Alternatively, if they are perceived to be dying in a way deemed to be 'inappropriate' - for example, exhibiting unpleasant physical

manifestations of their condition or making too much noise - they may be moved out of the public domain of the hospice ward into side rooms where they are less likely to offend (Mazer,1993). In her recent paper, Lawton (1998) graphically argues that today one of the functions of hospices is to sequester the 'unbounded body'; to hide away 'dirty dying' from the public view.

> Understanding the hospice as a 'no place' i.e. as a place within which the taboo processes of bodily disintegration and decay are sequestered, allows it to be understood as a central part of contemporary Western culture. Setting these phenomena apart from mainstream society enables certain ideas about living personhood and the hygienic, sanitised, somatically bounded body (Meyer:1991:265) to be symbolically enforced and maintained. (Lawton,1998,139)

Removing 'difficult' deaths from the public view in this way allows images of the Good Death to permeate further into popular images of deaths. In so doing, it may be argued that, hospices have a fundamental role to play in influencing attitudes and understandings of dying and death. So in what ways is the Good Death really 'good'?

> The Good Death.... is 'Good' in two fundamental senses. It is Good in a psychological sense, for the dying person who needs to restore or maintain order out of the frightening prospect of having his social existence destroyed. It is 'Good' for society, in a socially cohesive and ideological sense, for the deliberations of the dying will reinforce the reality, priority and value of the existing social order, and ratifying the dominant social ideas which support that order. (Kellehear,1990,60)

Perhaps the main purpose of the Good Death is its ability to give comfort to society about the nature of dying and death.

> I tried to make clear.....that the belief in the probability of death with dignity is our, and society's, attempt to deal with the reality of what is all too frequently a series of destructive events that involve by their very nature the disintegration of the dying person's humanity. I have not often seen much dignity in the process by which we die....The quest to achieve true dignity fails when our bodies fail. (Nuland,1993 Cited in Ahmedzai,1993,122)

Death as taboo?

My respondents were all living within a particular time and culture, therefore their experiences of dying were informed both by significant others' responses towards them, and more general pervasive societal attitudes towards dying and death. Given this, before considering the position of the dying individual in society it is useful to consider more general views about the subject of death. Ariès (1981) argues that there is a general attitude of fear towards dying and death within

modern Western societies. In addition, it would seem that death is something the majority of us feel uncomfortable talking about (Bond & Bond,1980). But how appropriate is it to talk of death as 'taboo'? Kellehear (1984) tries to address the question of whether we are a 'death denying society', he suggests that to say that the fear of death in society is universal is incorrect. He argues this on the basis that firstly, not everyone is afraid of death; secondly, that even amongst those who do fear death, their fear and image of death vary considerably; and finally, fear of death is not an inherent feature of human nature rather, he asserts, it is learnt by children from adults. Although due to increased medicalisation dying and death are now largely located, and consequently hidden, in institutions, in other ways since the 1960s there has been a 'rediscovery of death' (Vovelle,1980).

> It is now inappropriate to speak of the taboo placed on death in modern society....
> Today there is an increasing proliferation of literature indicating our "rediscovery" of
> death. (Kellehear,1984,715)

The interest which seems to surround the subject of dying and death, while supportive of the claim that death is no longer 'taboo', should still be viewed with caution.

> Despite the resurgence of academic and religious interest in the subject, as a society
> we remain characteristically uncomfortable with the facts of mortality.
> (Mellor & Shilling,1993,423)

Widely available material on dying and death does not, I would suggest, necessarily mean that people who read such texts (indeed even conduct research in this area) are well equipped to deal with dying and death on a personal level.

When discussing whether death is 'taboo', what is important is how one defines the term. Walter (1991) argues that a taboo may be something which is prohibited or forbidden by custom, rather than law, or it may be something which is so dreadful it should not be spoken of; or, in its weakest sense, a taboo could be argued to be something which is merely not mentioned in conversation. Death may indeed not be 'taboo' if it is taken to mean either of the former two definitions, however, the experiences of the dying and bereaved themselves indicate that others often find their close association with death a source of personal difficulty and embarrassment; people do

not know what to say, or how to react. Although, the increase of academic work and debate would point to the lack of 'taboo' it is useful to also examine in what ways it may be correct to assert that death is a taboo.

Walter (1991) suggests six arguments to explain in what ways death can be understood to be taboo. Firstly, 'taboo plus coda', this suggests that while death was a taboo it is now disintegrating. An example of this, Walter argues is the change of attitudes towards the dying during the 1960s amongst the middle classes; at this point people began to be viewed as 'courageous' if they spoke about their illness, rather remaining stoically silent which had previously been considered to be 'appropriate'. The second explanation Walter proffers links with the work of Blauner (1966).

> Blauner's thesis argues that death in modern society is not taboo; rather it is simply
> no great deal. It is not forbidden but hidden. (Walter,1991,301)

Today death rarely occurs in people's homes, it is institutionalised and sanitised; death is hidden away from public view, only those who need to, or choose to, need witness it.

Walter's third explanation concentrates upon the role of certain institutions in informing general perceptions about death. He argues that in modern Western society a 'limited taboo' may exist amongst certain groups, namely the media and medical establishment.

> Every time there is a disaster, it is not only reported, it is repeatedly reconstructed by
> the media..... the media have extraordinary power to interpret death for us.... It seems
> that the two professions to which our society has entrusted the interpretation and
> ritualisation of death - medicine and the media - are, or have been, almost uniquely
> embarrassed by the subject. It is therefore not so much society as a whole, but these
> two key institutions, for whom death is, or was, taboo. (Walter,1991,303)

With reference to medicine, Walter argues, death remains immune to increased technology, and consequently serves as a reminder of medicine's fallibility. The media, alternatively, have been seen to be responsible for the 'pornography of death'; death has now replaced sex within the collective consciousness of society as the ultimate taboo (Gorer,1955). Gorer's thesis suggests that in the 'pornography of death' death is portrayed without emotion. However, the recent death

of Princess Diana lends weight to Walter *et al's* claim that the media is 'like flies to a glowing light' (1995,584) when 'reporting' public deaths, and the emotions surrounding these events. What would appear to be true is that society's general understanding of death appears to no longer be particularly realistic, but rather is voyeuristic in nature - a point which is illustrated further by a seemingly widespread obsession with horror films and disasters. However, the media may also have a useful role to play in showing people how to respond when faced with dying and death in their own lives. Walter *et al* (1995) suggest that because British people no longer know how to grieve themselves, nor react towards the bereaved; it is of little surprise that the public turns to media representations for some guidance about 'appropriate' behaviour. The decline in traditional rituals surrounding dying and death has left the individual searching for new social 'rules' and 'norms'. Expressive grief seems to be more common today, but individuals are often unsure what will be tolerated. Given this confusion it is of little surprise that there is an:

> ....interest in learning from others how to present grief, especially when the role models are ordinary people who have only been catapulted into the glare of media attention often as a result of extraordinary death. (Walter *et al*,1995,593)

A notable exception to this general trend of looking towards 'ordinary people' for guidance, is the way British society and media looked to the royal family for guidance about how to behave in the wake of Diana's death[4]. Despite the prevalence of dying and death in popular culture and the media Mellor argues that death is not present in the public arena, the consequences of which are:

> The absence of death from public space makes its presence in private space an intense and potentially threatening one. (1993,21)

Walter *et al*'s discussion shows that they clearly disagree with this assertion:

> ......death is generally absent from private personal experience yet is very much institutionalised in public institutions. Death is publicly present but privately absent.....there is one arena that is very public and in which death makes a more-than daily appearance: the mass media....we argue that this is what really challenges the 'public absence of death' thesis. (1995,581)

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[4] The death of Princess Diana in 1997 is a particular, and peculiar, exhibition of very public mourning, not only of a community but also seemingly an entire society. Clearly events such as those witnessed last year are not commonplace and should be regarded as exceptional

As I shall illustrate further in Chapters 6 and 7, like Walter and colleagues, I also feel that death is 'privately absent', to the extent that the public presence of death appears to have little to offer to the dying and bereaved, who have to learn to manage difficult and strained social interactions.

Walter suggests that death may be viewed as taboo because of 'disparate frames'. "The experience of death is typically post-modern, in that meaning has become fragmented" (1991,303); we no longer have a common and coherent language available to discuss death, which leads to embarrassment and stilted conversation when the subject is raised. Death in this instance is neither a taboo nor invisible, but rather something individuals find confusing, and difficult to cope with. The problems which may arise in social interaction can partly be understood by considering Dumont and Foss' view:

> .....the characteristic avoidance of discussions of the topic may be due neither to indifference nor even to denial of death *per se*, but rather to the inevitable conflict generated by the cultural contradictions. (1977,99)

The public presence and private absence of death create difficulties in personal interactions which can be difficult to reconcile. However, death is not only a problem of modern societies, but, Walter argues, it is a 'universal taboo'. Citing the work of Becker (1973), he argues that denial of death is not merely the modern condition, but is the human condition. Like Walter, I feel that Dumont and Foss' (1977) thesis is particularly useful in understanding contemporary attitudes towards death; they argue that it is perfectly possible to both accept and deny death simultaneously. For society the denial of death is imperative if it is to function effectively on a day to day level; as individuals, however, it is important that we accept death if we are going to maintain any grip on reality and continue to function in our normal everyday lives and duties.

> On the intellectual-conscious level we accept death, since we are cognizant of "reality" and are therefore reminded that at any moment "we may be struck down". The unconscious-emotional level does not allow us to "feel" death, however, and it thereby provides a "delusion of vulnerability" which compels us to deny death by conceptualizing it as infinitely distant. (Dumont & Foss,1977,107)

Thus, it can be seen that at a cultural and individual level denial and acceptance of death have to exist concurrently if society is to function effectively. This certainly appears to go some way to

explain the proliferation of material published on this topic, which serves as evidence of death's existence and therefore ensures that individuals themselves are aware of its inevitability. At the same time, however, such reporting presents death as a problem for 'others' - something which therefore does not have any significant impact on the 'normal' running of society.

Finally, and perhaps most importantly for the purposes of my later discussion, both Kellehear (1984) and Walter (1991) draws a clear distinction between the attitudes and beliefs of the 'individual' and 'society' towards death.

> We are not a death-denying society. The arguments and examples to the contrary are unconvincing..... They do not separate out the issues of individual motivations, from group behaviours...... This confusion and projection of private ideas with public behaviors has led to an oversimplified and reductionist view of the relationship between the individual, society and death. (Kellehear,1984,720)

Developing this notion further, Walter asserts that it is the modern individual, not modern society who finds death difficult to deal with. Death no longer threatens society, because it remains linked with those who have little economic or social value to its continuing function (Glaser,1966; Turner,1995).

> It is a mistake to say that "modern society" can not cope with death; it deals with it very nicely thank you, with its elevation of youth, education and progress.....Today then, the dying and bereaved become uniquely isolated, lepers even, because they highlight the Achilles heel of the modern individual. (Walter,1991,306)

Increased secularisation, and the consequent decrease in religious and traditional rituals associated with death means that in modern society individuals are often left alone with their grief (and their dying). There are no longer pre-determined periods set aside for mourning as in previous eras (Littlewood,1992), which may itself have significant consequences for individuals:

> ...the individualisation and deritualization of bereavement make for serious problems in adjustment. (Blauner,1966,389)

> Death is so alarming in contemporary societies because modernity has deprived increasing numbers of people of the means of containing it in an overarching, existentially meaningful, ritual structure. The reflexive deconstruction of religious orders, that promised post-corporeal life after death, and the lack of stable replacement meaning systems, has tended to leave modern individuals exposed and unprotected in the face of their inevitable demise. (Mellor & Shilling,1993,427)

In contemporary British society community mourning is rarely seen, because, as I shall discuss later, in the main we are no longer greatly affected by any individual death[5]. Today, as a result, funerals tend to be family dominated, and the bereaved are left alone to learn to adapt and cope with their loss. Generally what is apparent in our society is that not only are the dying themselves isolated from the wider community, but individuals close to them may also be excluded and avoided. It is at this personal level that many people no longer know how to react to either the dying or the bereaved and consequently it is of little surprise that these groups often report being avoided by friends and family (Littlewood,1992; Cline,1995; Riches & Dawson,1996).

'Social death' and the isolation of the dying

Having discussed some of the processes by which dying and death are managed by society it would seem appropriate to examine what it may mean to be dying in contemporary Britain. The institutionalisation of death in hospitals or other health care environments has had a considerable effect on public understandings and attitudes towards dying and death:

> Today, the dying are second class citizens alongside drug addicts, convicts, alcoholics and disliked ethnic groups......Medicalising death has meant the transformation of the dying role into a low status, technology intensive and potentially contaminating situation in need of sanitising. (Kellehear,1984,717)

It seems the dying are often marginalised and isolated from the wider community, because there is a:

> ....peculiar embarrassment felt by the living in the presence of dying people. They often do not know what to say......For the dying this can be a bitter experience. While still alive, they are already deserted. (Elias,1985,23)

The dying not only serve as a physical manifestation of the fallibility of the human body, but also remind us of our own mortality.

The isolation of the dying may be intensified depending upon the age of the dying person. Today in many Western societies, as a result of general increased longevity, death is something which is

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[5] There are notable exceptions to this claim, for example community morning was seen in the case of the Hillsborough Disaster, the shootings at Dunblane, and, most recently, the death of Diana.

most commonly associated with the aged (Mulkay,1993). This change in the general character of the dying has meant that society is able to control, and consequently segregate, the group who are most likely to die, the aged, therefore 'protecting' itself from any potentially damaging disruption. Thus, the elderly, through a process of enforced life changes, are gradually marginalised from mainstream society.

> As people become elderly, they either through design or compulsion are forced out of traditional social roles involving full-time responsibility and commitment. As they withdraw from the social roles their reciprocity and integration with society declines and they.... lose a certain amount of prestige. (Turner,1995,122)

Effectively society devalues the aged (Blauner,1966): not only is it the case that at a pre-determined age individuals stop work, hence, having little influence on the economy, but also as individuals age so do their children, who stop requiring parental care. Changes in the family structure, increased social mobility and longer life expectancy have meant that although the majority of a person's dying may take place within the home (Field,1996) those who are dying are likely to experience this in relative isolation. All these facts serve effectively to minimise the impact the deaths of the elderly have on society because, not only are the dying physically isolated in the last few days and weeks of their lives, but they also likely to experience physical and emotional isolation at other times. However, it should be noted that these attitudes towards the aged are culturally specific, and perhaps also indicative of a secularised society. For example, in societies where the dead continue to hold importance and influence the tendency to isolate those who are assumed to be closer to death does not occur, and they actually acquire some of the value attributed to the dead (Blauner,1966; Mulkay & Ernst,1991; Cline,1995).

> ......[we] view death as a sort of failure, just as we now look at the process of ageing itself as a failure. We have lost, in this changed view, the old feeling of respect for dying and all the awe. (Thomas,1980,3)

Since dying and death do appear to be more commonly associated with the aged in society it is important to consider how integral society's notions and perceptions of age are to any discussion related to this topic. While it may be easy to minimise the social loss of the death of someone elderly by gradually diminishing their social status, it is not the case for someone younger.

> One of the consequences of devaluation of the old in modern society is the minimization of the disruption and moral shock death ordinarily brings about. But when people die who are engaged in the vital function of society....their importance can not easily be reduced. (Blauner,1966,381)

Before discussing deaths which do impact on the wider community it should be noted that although the death of a child may be upsetting for relatives and friends, Blauner (1966) suggests that as children do not have a significant role to play outside the immediate family unit, their deaths, like those of the elderly, do not have major implications for wider society.[6] Rather, Blauner argues, it is the middle aged whose deaths cause the greatest 'social vacuum', because it is this group who are most actively involved in society, the economy, and in rearing children. It is, therefore, the deaths of these individuals which are most likely to have a significant impact on the community. It is these deaths which are most likely to be characterised by large funerals, attended by members of the wider community; compare this with the invariably small, family dominated funerals of many elderly people.

What seems to be crucial in defining our perceptions and experiences of dying, death and bereavement is our understanding of what is an 'acceptable' age to die. The elderly are expected to die, hence, in general, their deaths do not affect many outside the immediate family. Younger people, conversely, are not expected to die, and therefore their deaths are likely to have a greater impact on the wider community, because:

> When death is associated with old age, young people can put off thinking about it: when they become aware that it may already be lurking in their bodies, and those of their sexual partners, its reality becomes more pressing. (Mellor & Shilling,1993,423)

Glaser (1966) refers to the impact of an individual's death as 'social loss'. In general 'social loss' is determined by a person's age, and therefore the extent to which past, present and future life potentials are fulfilled. Glaser (1966) discusses the different reactions of nurses dealing with the deaths of high social loss patients, for example in paediatrics, compared to the reactions of those working with low social loss patients in geriatrics. Glaser suggests that care for the elderly often

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[6] Obvious exceptions to this assertion are child murders which are generally widely reported by the media, and consequently have an impact on a much larger group of people.

only entails physical care rather than psychological and social care. He argues that this is a direct parallel with the dominant views of wider American society which seek to deny death, and avoid reminders and manifestations of the dying, resulting in the aged becoming isolated. At times these people may be rendered socially dead although still biologically alive (Glaser & Strauss,1965). Similarly, Sudnow (1967) also notes that others gradually withdraw from those individuals who are perceived to be dying, they are treated as though they are already dead. He uses the term 'social death' to refer to this state:

> A tentative distinction can be made between "clinical death": the appearance of "death signs" upon physical examination; "biological death": the cessation of cellular activity; and a third category, "social death" which, within the hospital setting, is marked by that point at which a patient is treated essentially as a corpse, though perhaps still "clinically" and "biologically" alive. (1967,74)

Sudnow goes on to describe a nurse closing the eyes of a patient, who she believed would soon die. By doing this the nurse ensured that when the patient was indeed dead, she would look 'appropriately' as though asleep. In addition this pre-death preparation meant that the problem of closing the eyes after death, which could prove problematic, would be avoided. Effectively, the alive patient was being treated as if she was already biologically dead. Today social death is likely to precede biological death when the death can be foreseen or is expected, for example in the deaths of the elderly or terminally ill. This marks a change, however, from the last century when, because of the unpredictably nature of death, social death often occurred after biological death. Long term degenerative and chronic illness, however, facilitates the process of what Fulton & Fulton (1971) refer to as 'anticipatory grief' - grieving for someone before their death - this in turn makes the likelihood of social death occurring before biological death more likely.[7]

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[7] It should be noted that certain groups may be affected more profoundly by 'social death' than others. For example, women, particularly married women, are more likely to experience social death than their male contemporaries. Not only do they experience the same enforced exclusion as men, but due to increased life-expectancy women are more likely than men to survive their partner. This means that they are also more likely to spend a number of years alone in widowhood - itself a form of social death (Mulkay & Ernst,1991; Littlewood,1992,1994).

In their respective discussions of the way in which the dying are gradually marginalised and excluded from normal social interaction, both Glaser and Strauss (1965) and Sudnow (1967) refer to Goffman's (1990a) concept of the 'non-person'. Goffman uses this term to describe the role of someone who is present during an interaction, but neither fully adopts the role of audience nor performer. There are several categories of people who may fall into the role of 'non-person':

> ...those in servant-like roles, there are [also] other standard categories of persons who are sometimes treated in their presence as if they were not there; the very young, the very old and the sick are common examples. (Goffman,1990a,151).

However, it is important to note that a 'non-person' is not necessarily ignored all the time, for example the servant may be ignored 'front stage' but contribute fully in other social encounters 'back stage' with other staff members. To this extent the 'non-person' can be said to have 'a simultaneous multiplicity of selves' (Goffman,1961,132).

> Goffman's essential insight is that our social existence is not necessarily continuous. As we come to occupy certain roles, we may temporarily drop out of the social world that is being created around us.... this process of social deconstruction may often be related in some way to people's biological condition, for instance, to their age or their state of health. (Mulkay & Ernst 1991,174)

This point is particularly pertinent to the experiences of the dying; to one category of people the dying may be regarded as being 'socially dead' but, at the same time they may remain 'socially alive' to others (Glaser & Strauss,1965; Sudnow,1967); they have a 'multiplicity of selves'. While Mulkay and Ernst acknowledge that previous work has indeed noted that social death can occur after biological death, they argue that the implications of this have not been fully explored. Accepting that the dying may be regarded in a variety of ways by different people, it is therefore necessary to examine the notion of 'social life' as well as 'social death'.

> The defining feature of social death is the cessation of the individual person as an active agent in others' lives.....individuals can be involved in numerous death sequences and may be, at the same time, dead for some parties yet socially alive for others. Social life is the obverse of social death and depends on the social continuation of the particular person, whether or not that person is biologically living. (Mulkay & Ernst,1991,178)

Just as social death may occur before biological death so social life can occur after it. For example a widow may continue to speak to her dead husband, effectively continuing her relationship with him despite the fact he is now no longer alive. Social life means involving the

dead in the experiences and activity of the living. This notion of 'social life' where individuals continue to have an identity and role after their deaths is particularly important to my discussion in Chapter 7 when I consider the ways in which respondents themselves referred to their status after death.

Identity, life-course and emotional work

Having considered the ways in which the dying may be treated by others it is important to consider what effects such behaviour may have on individuals themselves. This is of particular concern to the majority of my discussion in Chapters 6 and 7 when I consider respondents' attempts to manage their personal relationships. Central to my discussion in these chapters is the concept of 'self-identity', but linked to this are the notions of 'stigma' and 'lifecourse'. It is therefore useful at this point to elaborate on what is meant by each of these terms, beginning with self-identity.

> Identities are often personal and political projects in which we participate, empowered to a greater or lesser extent by resources of experience and ability, culture and social organisation. (Calhoun,1994,28)

Giddens argues that self-identity is not given, but rather "....it is a reflexively organised endeavour...which consists in the sustaining of coherent, yet continuously revised biographical narratives" (1991,5). In constructing our self-identity we compare ourselves to others during social interactions, not only this, but we also evaluate the ways in which others react towards us in order to establish our own position within the wider social structure.

> Human beings possess a reflexive capacity to imagine themselves (their self) in the way they see and observe objects external to them. (Kelly,1992,393)

Given this, it can be seen that how others react towards us is crucial in our construction and maintenance of self-identity, for example if others react towards us in a negative way this may affect our concept of self-identity and cause us to 'revise' it in some way.

Mellor and Shilling (1993) state that central to this reordering of narratives is our embodied biography.

....a central prerequisite for the development of the human (i.e. social) being is the control of the physical body and its capacities. Such control and the knowledge it brings provide a sense of constancy of the embodied self and the ability to plan and predict future actions. (Kelly & Field,1996,244)

The 'body' has increasingly become a central concern in people's lives. There is an emphasis in contemporary Western cultures for the body to be youthful and 'attractive' (Featherstone,1982); a body which does not fit societal ideals is perceived to be due to individual failings. This 'culture of the body' has specific implications for the dying because:

The more people prioritise issues relating to self-identity and the body, the more difficult it will be for them to cope with the ideology of the self-ceasing to exist. (Mellor & Shilling,1993,414)

Despite the fact our bodies are an integral part of our self-identity, in the main, our bodily experiences often have a 'background' role in 'normal' everyday life. It is only when the body ceases to function in the way expected that this aspect of a person's taken-for-granted self-identity is brought into focus (Kelly,1992). Not only is the body a crucial factor in our own personal life and experience, but, as Goffman (1990a, 1990b) notes, our outward bodily appearance is important as it is on this basis that others appraise us, and upon which our identities depend. If something happens to change our outward facade the consequences can be profound:

It is generally the case that if a person's bodily appearance and management categorizes them as a 'failed' member of society by others they will internalize that label and incorporate it into a 'spoiled' self-identity. (Shilling,1993,85)

I suggest later in this thesis that although respondents' bodies experienced and endured their cancer and its treatments, individuals themselves appeared to conceive of themselves as more than bodies. This links with the work of Mulkay and Ernst who cite Turner's assertion that individuals are indeed able to exist in what he refers to as 'disembodied' form (1995,234). Clearly this concept of 'disembodied' self-identity is also important to my earlier reference to 'social life' occurring after 'biological death', because:

The idea of social life after biological death requires us to conceive of social actors as separable from their bodies. (Mulkay & Ernst,1991,177)

Like other chronic illnesses, cancer gradually (generally) erodes an individual's bodily capabilities. Confronted with such change individuals may need to re-think and redefine their own biography in order to make sense of their new experiences (Bury,1982; Williams,1984). Given this, it is not surprising to note that the diagnosis of cancer is likely to have a profound effect on an individual's self-identity:

> .... the individual's specific perception of the self as a person who has to live with cancer influences his/her ongoing evaluation of the social environment. Conversely response of the social world to the individual who now has a new dimension added to his/her identity - that of being 'cancer patient' - frequently have a significant impact on the individual's feelings of self-worth, competence and personal power. (Fife,1994,313)

As I shall illustrate in Chapter 6 a diagnosis of cancer can be seen to be a stigma. A stigma is "an undesired differentness" (Goffman,1990b,15), it means that one is "disqualified from full social acceptance" (9). A stigmatised condition, like cancer, potentially, "both depersonalises us and writes us off as individuals by implying or disabling our identity" (Sutherland,1981,13). Being a 'cancer patient' means that other aspects of an individual's self-identity may be negated or ignored; 'cancer' effectively becomes their 'master status', the primary identity on the basis of which others interact with them. That cancer and death are often closely linked in the public imagination, and that dying and death are often difficult to manage at an individual level, account, in part, for the fact that cancer can be regarded as being a stigma. That cancer, and a subsequent dying status, may be considered to be a such, is further understood when one notes that dying is not a valued status (Field,1996):

> The process of dying.........cannot be seen as anything other than the incipient loss of control: death is unintelligible exactly because it is the point zero at which control lapses. (Giddens,1991,203)

Dying, as already noted, is associated with both individuals who are generally devalued and marginalised from main stream society and a loss of social roles and social value. This means that the experience of dying results in a negative (often) change in self-identity. Such change, as Chapter 7 illustrates, requires skill and effort in order to 'manage' it effectively.

Having a terminal prognosis places one outside the 'normal' experiences of others. Death means that one no longer has a future and in a society which is future-oriented this is problematic. Individuals are expected to structure and plan for their future; discovering that one is dying, and therefore has a limited future, stands in conflict with pervasive societal expectations (Mellor & Shilling,1993). A diagnosis of cancer, therefore, is likely to have a considerable impact on an individual's life. In my later discussion I use the term 'lifecourse' to refer to the life events experienced by an individual, rather than the term 'life-cycle'. The life-cycle implies an ideal sequences of events through which individuals pass as they age. Contemporary life, however, is not so predictable. Cotterill (1994) argues that the life cycle approach does not account for 'unplanned' events such as death, divorce or pre-marriage pregnancy which disrupt this 'ideal' order of life events and create lives which are in some way 'different'. She goes on to suggest that the term 'lifecourse' is more useful because this:

....encompasses social and demographic changes which affect all our lives, as well as the personal biographical events in each individual's lifecourse (1994,112)

Although I also use the term 'lifecourse' in my discussion it is, however, still important to note that certain life-events continue to have significant consequences for individuals. Giddens (1991) notes that individuals have the capacity to react to such unexpected events and incorporate them into the reflexive construction of self-identity. However, in order to plan and reflexively engage in daily life individuals must continue to have certain taken for granted assumptions about their own lives. For example in the daily process of planning and reordering our lives there is the assumption that we will be alive to put such plans into action and to see their outcomes. Further given general increased longevity in society there is also the assumption that we will be alive longer to fulfil more goals; the future and planning for it, as already noted, are important features of modern life. A diagnosis of cancer, particularly, at a relatively young age disrupts an individual in the process of reflexively constructing self-identity and planning for the future. In addition such an event has an impact on others, as it causes them to reassess their own taken for granted

assumptions about life.[8] As noted earlier death in the elderly does not threaten the young, however, when it occurs in their contemporaries it causes difficulties (Mellor & Shilling,1993).

In order to manage the potentially damaging effects of their cancer and dying status I argue in Chapter 7 that respondents engaged in 'emotional work'. Hochschild, in her study of flight attendants, makes a distinction between emotional labour, emotional work, and emotional management. She says,

> ... *emotional labor* [means] the management of feeling to create a publicly observable facial and bodily display; emotional labor is sold for a wage and therefore has *exchange value*...The synonymous terms *emotional work* or *emotional management* ...refer to these same acts done in a private context where they have *use value*.(1983,7)

James (1989,1992) uses the term emotional labour to describe both the paid and unpaid work which women (predominantly) undertake within the private and public sphere. Further, Strauss *et al* (1982) use the term 'sentimental work' and Lynch the term 'solidary labour' to describe similar concepts:

> Solidary labour is a form of symbolic labour. It is not labour which is productive either of cash profit or any other material good. The motivating force behind solidary labour or love labour is not an economic one, rather it is symbolic; the promotion of the bond *per se* is the goal of solidary labour. (Lynch,1989,5-6)

In the following chapters I incorporate the above definitions and descriptions within the term 'emotional work'. I use this phrase to describe the skill and effort required to deal with people's feeling - both the individual's own and those of others - within the private sphere primarily in close personal relationships.[9]

Emotional work in either the public or private sphere is often seen to be 'gendered' as it is considered to be the responsibility of women (Duncombe & Marsden,1993; Frith &

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[8] I am not implying that the elderly would not also feel that a diagnosis of cancer disrupted their lifecourse. Indeed Fife (1991) notes that elderly people as well as younger people can feel frustrated by the fact a diagnosis of this kind prevents them fulfilling plans they had made.

[9] Although this discussion centres primarily on emotional work which took place within the private sphere that is not to say that respondents did not also engage in the same labour at other times within a more public arena.

Kitzinger,1998). It is difficult to comment on this within the context of my own research because there was only one man in the study group. However, in my later discussion it does seem that the emotional work of the women did fit with stereotypical notions of the nature of the female role in terms of nurturing, and caring for the needs of others (Graham,1983). James (1989) argues that women are often assigned the responsibility of emotional work because they are assumed to be 'naturally' more emotional than men, and consequently 'naturally' better at dealing with emotions. Not only is such labour gendered, but it is also difficult to describe and define, James uses the words of a female doctor to illustrate this point. The doctor said:

> I couldn't write a book on how to deal with patients who are ill, and who have a terminal illness and family problems. I couldn't write it down. I just think it's just something with each patient, and you have to sort of use your instinct to know what they want back from you. I think it's something so ill-defined. (James,1989,16)

Emotional work often remains invisible within the home - only noticed when it is not done (Graham,1983) - and when present within the public sphere remains difficult to define. These facts and also that emotional work is assumed to be a 'natural' role or responsibility of women means that its significance often either neglected or ignored (James,1989).

Dying means that one's self-identity is likely to be irrevocably changed, but, also more importantly, damaged. Again, what becomes important in later chapters is how individuals managed their self-identities in order to try to maintain normal social interactions for as long as possible. Death may indeed be no future but as Lofland notes:

> .....if we know anything about humans, we know that they do not confront meaningless situations for very long. In the face of meaninglessness, they construct for themselves new sets of beliefs, new orientation, new ways of looking and feeling which fill the void. (1978,36)

Further, another related point, is the extent to which the narratives that respondents presented may be seen in terms of what Seale (1995a) refers to as an 'heroic' script. Seale argues, in line with Lofland, that dying can be incorporated into the reflexive formations of self-identity.

> An open awareness of dying is an affirmation of the project of self in the face of the ultimate threat of selfhood. This is a particular difficult, but also a particularly necessary, achievement where religion and other traditional narratives no longer sustain the individual. (1995a,606)

He goes on to suggest that certain types of death, namely cancer and AIDS, are particularly suited to being labelled as 'heroic deaths'. Often individuals dying of these illnesses will apparently confront particular difficult issues, before reaching a state of 'awareness', with their dying often ultimately being characterised by others as one of 'dignity'. Seale suggests that this is in stark contrast to the deaths of the institutionalised who have less ability to develop an heroic script, rather their deaths are more commonly characterised as the antithesis of dying with dignity and have become "the horror stories of our time" (1995a,612). Seale goes on to note that the labour that takes place in the formation of an heroic script at this time may be viewed as being essentially female in character, since it deviates from more traditional notions of masculine heroics:

> ...the heroic life is the sphere of danger, violence and the courting of risk whereas everyday life is the sphere of women, reproduction and care. (Featherstone,1992,165)

> ....the emotional work in reaching acceptance of death and caring talk and emotional accompaniment..... became opportunities to demonstrate female heroics of care, concern, and emotional expression. (Seale,1995a,611)

In Chapters 6 and 7 I consider this argument in more detail by discussing to what extent the term 'heroic death' is an appropriate term to use within the context of my own data.

At a general societal level it seems that dying and death can be effectively managed through the process of sequestration (Mellor,1993); individuals who are most likely to die are gradually marginalised, and death itself is institutionalised. 'Hiding' death in this way does not mean that the reality of death is denied, indeed its 'reality' is to reaffirmed by abundant popular and academic coverage and debate. But what of the dying and those close to them? The aim of my research ,and the main purpose of this thesis, is to examine the experiences of those individuals living with a terminal illness. How respondents lived with their prognosis and learned to manage their dying status is discussed later. Whatever the situation regarding the public absence or presence of death, the following points would still seem to be particularly true:

> Individuals are likely to experience the tension between the public and private presence [of death] particularly strongly when they find themselves alone with the task of not merely constructing meaning, but of even knowing how to act, when they are faced with the deaths of those they care about. (Mellor,1993,20)

The sentiments of modern society rarely equip its members with first hand evidence of our common mortality. (Riches & Dawson,1996,151)

However, before discussing my data, in Chapters 2 and 3 I consider the ethical and methodological problems raised during the fieldwork process.

Chapter 2

Practicalities of the Fieldwork Process

In this chapter and the next I address different aspects of the research process. While there is some over-lap between the two chapters, I feel that dividing the methodology section in this way is appropriate as each chapter takes a different approach in discussing issues relevant to the methods and methodology of this research. In this chapter I discuss the actual research process and in Chapter 3 I consider theoretical influences and implications of the method I used. In this first chapter I describe and document the fieldwork process as it evolved: from gaining access, to interviews, to leaving the field. I will also introduce respondents, firstly, by providing a description of the characteristics of the study group as a whole, and secondly by giving short biographical notes about each individual.

Original plan

This is a qualitative study which seeks to explore the experiences of living with a terminal illness from the dying individual's perspective. Initially I envisaged recruiting 15-20 patients, under 65, male and female, with an estimated remaining life span of 6 months. I hoped to interview a sub-section of my study group at least a second time after a period of approximately two months. My inability to specify the size of the subject group in advance was attributable to a number of factors: firstly, time constraints of the actual research period; secondly, the time it would actually take to recruit respondents who fitted my criteria; and thirdly, the aim of this research was to develop a theory which was rooted in the empirical data collected, and it was therefore difficult to estimate in advance how many respondents would be needed before any emerging theory could be viewed as being valid (Glaser & Strauss,1967)[1]. I wanted to explore the experiences of younger patients (under 65) because these people would not normally be expected to be dying, given the

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[1] My specific theoretical approach to data gathering and analysis is discussed in more detail in the next chapter.

evidence which suggests that most of us should now live well past our seventieth birthday (Office of National Statistics,1997). As a result of this I thought it would be particularly interesting to explore their feelings and reactions to both their original diagnosis, and to consider the subsequent impact it had on their lives. I did not make any specification with regard to gender because my original aim was to explore the experiences of the dying, and not just dying women or dying men. I was aware from the outset that cancer is not a static disease, neither is it predictable in the way it affects an individual both in physical and emotional terms (Bryant & Payne,1993). Such realities would obviously have a bearing on both recruiting and the length of time an individual would be able to participate in the research. With this point in mind, I decided to try to recruit individuals with an expected remaining life span of about 6 months. I hoped that this would mean that individuals would be well enough to be interviewed in the first instance; and that it would be possible to re-interview a sub-section of the original study group. I envisaged that repeated interviews would have a number of functions: to explore how feelings, experiences and beliefs had or had not changed over time; to allow me to develop or clarify points made in the first interview; and also to enable me to explore emerging themes and issues with respondents in more detail.

Negotiating access

Gaining access to a hospice, my chosen research site, involved coming into contact with various 'gatekeepers'.

> Gatekeepers are those individuals that have the power to grant or withhold access to people or situations for the purpose of research. (Burgess,1984,48)

Two 'gatekeepers' I encountered are best described by Homan:

> .....those gatekeepers who control spatial access and perhaps some kind of right, or legal responsibility which obliges the social researcher to approach them in a formal way. The gate is that which opens up the field. (1991,82)

In the first instance, I was put in contact with the Medical Director of LOROS/The Leicestershire Hospice[2] and we arranged to meet to discuss my research proposal; he was interested in my research, and agreed to allow me to interview hospice patients. Before beginning my fieldwork, however, he left his post and it was therefore necessary for me to negotiate access with his successor; again my request was granted. I also had to submit my research proposal to the local Health Authority Ethics Committee, another gatekeeper, for its approval. A few days after the Committee sat I received written notice that my research had been approved without any conditions being imposed. However, there is not necessarily only one 'gatekeeper' in any institution, rather:

> ....we need to think in terms of gatekeepers who can grant permission for the researcher to study different facets of the organisation. (Burgess,1984,49)

More specifically as Lee points out:

> Physical access is a precondition of social access. With the former secured, however, the latter can remain problematic......it is assumed that superiors have the right to permit their subordinates to be studied. Often, however, this consent, once given, produces little more than the token co-operation of subordinates. (1993,133)

With this point in mind, it was decided that it would be beneficial for me to spend some time at the hospice prior to commencing field work, and a consultant at the hospice arranged a two week 'induction' for me. This time was spent meeting and 'shadowing' various people with different responsibilities and roles. The time was useful in that it gave me a better understanding of the way in which the hospice service worked, as well as allowing people at different levels to get to know me, and ask questions about my research. With hindsight, I feel this initial period, coupled with regular contact and communication with hospice staff, went a long way in ensuring the success of my fieldwork period.

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[2]LOROS - (Leicestershire Organisation for the Relief of Suffering) is a charity which was set up in 1977 to provide hospice care. It comprises both The Leicestershire Hospice and Manor Croft Day Centre (opened in 1985). Like many other hospice organisations it provides a variety of services for both patients and their families including: Home Care, Day Care, Outpatient Care and Counselling (LOROS Information Leaflet). In some discussions I refer to LOROS, this should be taken to mean that I am discussing the organisation in general rather than one particular aspect of it.

Forming a Study Group

To obtain my study group, however, I required the help of more gatekeepers, namely the Home

Care Team (HCT) and the Day Care Centre (DCC). Homan identifies this type of gatekeeper as:

> ....[an] intermediary between researcher and subject.... engaged to introduce the research task and purpose either to those who exercise the right to give clearance or to the subjects themselves. (1991,84)

It was this latter task of actually introducing the research to potential respondents that the HCT

were involved with. The DCC staff tended to introduce me to potential respondents, and I then

approached people personally. I was advised that these two services would be of most use to me

given the characteristics of the study group I sought. The HCT comprises four nursing Sisters.

Although doctors are also involved, patients have more regular and frequent contact with their HC

Sister. The HCT's aim is to provide care within the home environment to enable individuals who

want to stay at home to do so, which means they often work alongside General Practitioners and

Community Nurses. The DCC offers care and support for those who attend the centre, as well as

providing a break for carers. One of the aims of the DCC is to enable patients to maintain their

independence and to live as normal a life as possible (LOROS Information Leaflets). Both the

HCT and DCC have frequent contact with a wide variety of patients, and while their services

often do overlap, in that someone may see their HC Sister regularly and attend the DCC, this is

not always the case. This difference in patients provided a broader basis from which to form a

study group.

I spent some time with both services explaining the aims of my research, and the criteria I hoped

to use in selecting respondents. I asked the HCT to approach individuals who fitted these criteria,

to ask if they would be interested in taking part, and, if they were, to give them a letter I had

written explaining the research and what it would entail in a little more detail. I attached a form to

this letter which patients could fill in if they wanted to take part. The DCC recruiting was much

the same, although after being introduced by a member of staff, I was the person who actually

approached people to ask if they would be willing to participate.

> The likelihood is that intermediaries of this kind will be chosen not only because they can present the proposed research in an intelligible way but because they will do so sympathetically and assure subjects of its good intentions and relative harmlessness. (Homan,1991,84)

The HCT, by approaching individuals, did this in a more overt way than the DCC staff, but never-the-less the same implication was apparent. However, this was not the only advantage of being introduced by others, as Cornwell points out:

> Having personal introductions made the initial contact with people much easier and helped to make the atmosphere surrounding the interviews much less formal than it might otherwise have been. (1984,3)

Help from others was not only important in terms of the credibility and subsequent relationship I developed with respondents, but was also a crucial factor in my own research experience. Both groups provided a great deal of ancillary information which I needed at times, as well as much valued advice and emotional support.

Once I received completed forms I contacted potential respondents as quickly as possible, and asked firstly if they were still willing to take part, and then, if they were still in agreement, I arranged an acceptable time and place to conduct the first interview. I felt that by approaching people in this way respondents were giving their 'informed consent' in participating in the research:

> The essence of the principle of informed consent is that the human subjects of research should be allowed to agree or refuse to participate in the light of comprehensive information, concerning the nature and purpose of the research. (Homan,1991,69)

All potential respondents were given the time to read over a letter explaining the aim of the research, in their own time and without being pressurised, before deciding whether they wanted to take part in my study. Further, prior to beginning each interview all respondents gave me their oral consent to participate in the research.

At the beginning of the fieldwork I felt that recruiting potential respondents through the HCT was preferable to using the DCC. I believed that asking the HC Sisters to approach their patients,

would give people more time to think about whether they really wanted to be involved. At the DCC I was worried that people would feel under some kind of pressure to take part because they were actually being approached by myself, the researcher. Despite this concern feedback via the HCT, DCC, and sometimes directly to me, was positive. One respondent told her HC Sister that she had enjoyed talking to me because she knew it was confidential, and she could say things to me which she knew would not be repeated to those involved with her care. With hindsight I feel that the combination of the two approaches was very useful, the majority of patients the HCT recruited did not attend the DCC, and in general had poorer prognoses; in comparison, some of the patients I recruited only attended the DCC, and therefore would have been missed had I used the HCT alone. These patients tended to have better prognoses, indeed some of the patients had been attending the DCC for a number of years and three told me they were in 'remission'.[3] Originally I had never anticipated recruiting patients in 'remission', because it had never occurred to me that a hospice would provide care for anyone apart from those who were dying. However, these accounts have proved to be equally as informative and valuable as those of individuals with poorer prognoses.

Only one individual when initially approached by the HCT declined to take part. Another person who had agreed to take part, told me when I arrived at his house, as arranged, that he had to go out and therefore could not take part in the interview. When I offered to arrange another time to come back it became obvious that he really did not want to take part. At the DCC, when approached, two patients said straight away that they would prefer not to take part, and a third woman agreed to take part but later withdrew. The reasons all three women gave was that they would prefer not to talk about their illness, implicit from this is the fact that my study group undoubtedly consisted of people who did feel reasonably comfortable talking about their illness and its effects on their lives, consequently my research lacks the contribution of those individuals who do not want to talk. Although I think it is important to state that there were individuals who

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[3] Since completing my fieldwork only one respondent has remained in 'remission' and not undergone any further treatment (see later for further detail).

declined to take part for a variety of reasons, as I discuss further in the next chapter, I feel that this does not affect the validity of my discussion.

Recruiting the study group took 9 months, and the fieldwork lasted 13 months. Recruiting and fieldwork occurred concurrently. At different times during the fieldwork period a number of respondents were recruited within a short time, at other points it was several months before a potential new respondent was approached. Difficulties in recruiting were obviously related to the criteria I had specified. Age was very important in determining whether patients would be approached; as I noted in my introduction, generally hospice patients tend to be older than the group I hoped to interview, and consequently this meant that there was usually only a small number of patients at any one time who could be included in the study. Another factor which made forming the study group difficult was that, on occasions, people who were perhaps in the age range I hoped to interview were too ill to take part in my research when they were referred to the hospice.

I maintained regular contact with both the HCT and DCC throughout my fieldwork. This was done in a formal way, for example, having brief meetings to discuss how people felt the research was progressing. This kind of contact was more frequent in the early stages of my research, as I hoped that through these meetings I would be able to identify any unanticipated problems. I also was aware of Burgess' comments that:

> There [is a] continuous process of negotiation and re-negotiation throughout the research. Research access is not merely granted or withheld at one particular point in time but is on going with the research. (1984,49)

On a more informal level I used to call in regularly both at the DCC, where I used to chat to both patients and staff, and at the HCT's office. I felt this contact was very important if I was to sustain the co-operation, help and enthusiasm of both the DCC and HCT over a period of time. After I had finished my fieldwork I arranged to speak to the HCT in order to 'debrief' (I did not have such a formal meeting with staff at the DCC because their recruiting role was more informal). I

wanted to get some feedback about their perceptions of the research. Initially one HC Sister said she felt, "Oh no, not another piece of research". However, she and the rest of the HCT felt that because I had maintained regular contact and informed them of the research's development that this had helped to ease their original concerns. Further, my frequent contact also ensured that they did not forget about the research, and remembered to approach potential respondents. Hornsby-Smith (1993) argues that a researcher needs to be persistent if she or he is to overcome any access difficulties. I would argue, that such persistence is important throughout the fieldwork period, if good relationships with both gatekeepers and respondents are to be maintained.

The aim of the research also helped to gain the HCT's support and enthusiasm. They said they particularly liked the fact that I was asking people what they 'felt', what their experiences were, rather than imposing a more prescriptive questionnaire. It may be useful to speculate that the methods a researcher employs may go some way to improve both the possibility of being allowed access initially, and the likelihood of maintaining continued co-operation; this was certainly my own experience. Respondents themselves also went a considerable way to ensure the continued co-operation of the HCT, by giving the HC staff positive feedback. The only problem the HCT voiced was about the age group I had specified, because at times it was difficult to recruit patients within this age range. One Sister in particular felt that older people also had their stories and views to tell, and that perhaps younger patients were reacted to differently by staff because of their age and consequently made to feel more special - although she said she knew this was not supposed to occur. I accept this point and realise that my data may be age specific to some degree. However, overall I was pleased to find that the HCT had such positive feelings about the research, and I remain extremely grateful to both them and the DCC for all their help, time and support.

The study group

All respondents have been given pseudonyms, like Cannon (1988), I spent a long time giving people names which I felt suited them.

> I chose a name which I thought suited their age and personality. Some women chose names which I thought did not suit them and, although I tried, I could not become comfortable working with these names which seemed so incongruous against my mental picture of the women. (Cannon,1988,53)

Unlike Cannon I decided early on in my research to choose the pseudonyms myself, as a result all the names are personally relevant to me. Sometimes I simply chose a name which I felt 'suited' the image I had of a particular person, at other times I gave respondents names because they reminded me of someone I knew, for example, they were a similar age or had the same sense of humour. To the majority of people my respondents will be anonymous, however, I am aware that as my study group comes from one organisation, and that there are only a small number of people involved, identifying individuals by their age, symptoms, and family background may be relatively easy for some. I believe there are varying degrees of anonymity in any research. Often people are still able to recognise their loved ones or patients, despite efforts to the contrary. With reference to my own research, it may indeed be the case that some individuals are recognisable to a few people, because although I have changed respondents' names I have kept other biographical details, such as age or family circumstances. I have done this because to change these details would be impossible given the nature of the accounts I present. Further as these facts become apparent later in my discussion, trying to avoid noting them at this stage serves little purpose. Despite this, it is likely that some respondents still remain more anonymous than others. For example, some people may be more easily recognisable because of their age or diagnosis, and others less so.

In this section I begin by providing a description of the whole study group, and then I introduce each person individually. My study group comprised nineteen hospice patients, ten respondents had contact with the HCT only, five with only the DCC, and four had regular contact with both. There were eighteen women and one man in the study group, aged 27-67, the majority (13) were aged between 43 and 57. All respondents had been diagnosed with cancer, some for the first time over 16 years ago, others only within a few months of us first meeting. Diagnoses varied: ten people were diagnosed with breast cancer, four ovarian cancer, one myeloma, one lyposarcoma,

one Hodgkin's Disease, one cancer of the oesophagus, and one cancer of the stomach. Three respondents told me they were in 'remission'. Fourteen respondents were married, three divorced and two single. Eighteen respondents had children and eight were grandparents. Eleven still had their children living at home with them, and five respondents had children under 16 years of age. Nine respondents had to give up paid employment because of their illness, although all the study group found that their role within the home had altered to some extent as a result of their illness. By the end of my fieldwork eleven people had died, three remained in remission, and another five respondents were still living with their terminal cancer.

Liz was 62 and had been diagnosed with cancer of the oesophagus in 1993. She lived with her husband, and had children and grandchildren who lived away. She was interviewed on two occasions, once at her home, and once on the hospice ward. Liz died shortly after her second interview in the hospice, at the end of 1995.

Anna was 44 and was first diagnosed with breast cancer in 1989. She underwent surgery and treatment for this and for a number of years she had been symptom free. In 1994 she discovered she had ovarian cancer. Anna was married with children, some of whom still lived at home, and she was also a grandmother. I met Anna twice at her home and she spoke at length each time. She died shortly after her second interview, at home as she had wanted, in the winter of 1995.

Roger was 56, he first began to feel 'unwell' four months earlier, and was diagnosed with cancer of the stomach two months before we met. He did not have any surgery or treatment. He was married with one young child. I interviewed Roger only once, but I spent five hours at his home. He was too ill to face a second interview, and died at home in early 1996.

Sarah was the youngest respondent at 27. She had first discovered a lump in her breast in 1992, but she was told this was 'nothing to worry about'. Shortly after the birth of her second child she

was diagnosed with breast cancer. She had a partner, but she lived alone with her young children. I spoke to Sarah informally on various occasions at the DCC, and actually interviewed her three times. She died in the summer of 1996.

Margaret also had cancer of the breast, she had first discovered a lump four years previously, and since then she had been told she had secondary cancers. She was 67 and married, her children no longer lived with her. I interviewed Margaret once, she was having difficulties with her speech at the time of her interview and was not felt to be well enough for a second interview; she too has subsequently died.

Ann was 34, she first consulted a doctor in 1992 because she was feeling 'unwell', however, it took a few months to confirm that she had Hodgkin's Disease. She was married with young children. Ann was interviewed on three occasions and I also often spoke to her informally at the DCC. At the end of the fieldwork she was still alive.

Gill was 57 and diagnosed with breast cancer, she first discovered a lump four years before. She lived with her husband and children. Gill was interviewed twice: the first time her husband was present, the second time we were alone at first before her husband came in. At the end of my fieldwork she was still alive.

Edna was 49, she was first diagnosed with breast cancer at the end of 1992. She had successfully undergone treatment, and had been told me she was now in 'remission'. She was divorced and lives alone, but she has children and grandchildren.

Roz was 51 and had first become 'unwell' the year before we met. She had been diagnosed with ovarian cancer, although she told me she was now in 'remission'. She was married and had children, one of whom was still young and lived at home.

Pat was 47, her symptoms first began in 1994, although it took some time to discover that she had myeloma. She was married and her children still live at home. At the time of her interview she also said she was in 'remission'. Edna, Pat and Roz were interviewed only once, because they all told me they were in 'remission'. They gave long detailed accounts of their experience of living with cancer. At the end of the fieldwork they were all alive.

Rachel was 53 she first began to feel 'unwell' in 1993 and was later diagnosed with ovarian cancer. She was married and had children who no longer lived at home. I interviewed Rachel twice in her home, the second time her husband was present. Shortly after her second interview she was admitted into the hospice, where she eventually died.

Ruth was 37 and married with young children. She had first consulted a doctor nine months earlier, however, it was only three months before our meeting that she discovered she had breast cancer and secondary cancers. She was interviewed only once because she seemed reluctant to continue being involved in the study. At the end of my fieldwork she was still alive.

Karen was 51, she too had cancer of the breast. She first discovered a lump in 1991, she consulted her doctor a number of times before eventually being diagnosed. When we met she too had secondary cancer. She lived with her husband and children. I interviewed Karen only once, I was later informed that she had been upset by talking about her illness. She died a few months after we met.

Heather was 62 year old single woman who had breast cancer. She had first been diagnosed sixteen years ago, and had undergone surgery. Since then she had continued to live her life normally and symptom free, until discovering the previous summer that her cancer had returned. Heather and I spoke only once, she seemed uncomfortable speaking at great length, preferring

short answers, and seemed uncertain about any future participation. Heather died in the summer of 1996.

Katie was 50, she first began to suspect that something may be 'wrong' in 1993, and was subsequently diagnosed with ovarian cancer. She lived with her husband and children. I visited Katie on three occasions, she was very open, speaking at great length about her experiences. At the end of my fieldwork she was still alive.

Gail was 43 and had lyposarcoma. She first became ill in 1991 when she underwent surgery and treatment, in 1994 she discovered that her cancer had returned. She was divorced and had children and grandchildren. Gail was interviewed only once at home in her bedroom, she was too ill for a second interview and died in the summer of 1996.

Judy was 50, she had been feeling 'unwell' for a number of years, but it was in 1994 that she discovered a lump in her breast, and was later diagnosed with cancer of the breast. She was also married and had children who lived at home. I interviewed Judy while she was on the hospice ward. She was too ill for a second interview and died shortly after I met her.

Gaynor was 48, she had first consulted a doctor six years earlier, although it had taken a few months for her breast cancer to be diagnosed. She underwent treatment and was able to continue living her life normally. Seven months before our meeting she had been diagnosed with secondary cancer in her bones. She was married and some of her children still lived at home. I interviewed Gaynor only once. The day I called to arrange a second interview she had just been admitted into the hospice, and she died a short time afterwards.

Rebecca was 53 and had first been diagnosed with breast cancer sixteen years before. For thirteen years she had been 'clear' of cancer, but two years prior to our meeting she had been diagnosed

with secondary cancer in her bones. Rebecca was divorced and had children and grandchildren, she became part of the study group towards the end of my research, and I interviewed her on two occasions. She was still alive at the end of my fieldwork.

The interviews

All respondents lived in Leicestershire, so much of my fieldwork period driving around, with the Leicester A-Z within easy grasp. Further, all the interviews were conducted at a location and time convenient to respondents. The majority of interviews took place in respondents' homes, presumably where they felt most at ease (two took place on the hospice ward). I tried to arrange a time which was convenient for respondents and also when we would be least disturbed. Respondents tended to prefer that I come in the afternoon (when they felt at their best), and during the week (when we could be alone). I called the evening before I was due to go to interview respondents to make sure that the everything was still alright, and they were still willing to take part. One woman withdrew from the study at this stage. I tried to avoid conducting more than one interview in one day, because each interview was draining in terms of both listening and concentrating, but also the emotions involved. However, it was, necessary on one occasion for me to interview two people on the same day. All interviews were audio-taped:

> The use of a tape recorder has several advantages: (1) it permits more complete and accurate transcription of the interview material, and (2) it allows the interviewer greater freedom to concentrate and become involved with the interview situation, by eliminating the need to be concerned with the problems of recall and/or notetaking. (Laslett & Rapaport,1975,972)

Four respondents had another person present while we spoke, although this was not the ideal situation I had envisaged I respected their wishes. Brannen (1988) points out that respondents may find talking and thinking about what has happened to them a stressful experience. Throughout my research I attempted, as far as possible, to minimise respondents' anxieties, and I tried to make each person feel comfortable during the interview.

Before beginning each interview I spent some time explaining that I would be speaking to a number of hospice patients, and I wanted to talk about their experiences of living with cancer. I explained that there were no right or wrong answers, what I wanted to learn about were their own experiences and feelings. Further, in line with procedures laid down by the Health Authority Ethics Committee, I obtained oral consent from respondents before the interview commenced. I explained that I would like to tape the interview, but if preferred I would take notes. I said participation was entirely voluntary; not taking part or withdrawing from the study would not affect future medical care in any way. I explained that all information would be treated confidentially, and respondents would never be identified by their name, and only I would ever listen to the tapes. I then asked respondents if they had any questions they would like to ask. At this point no-one withdrew from the study, and no-one said they would prefer me to take notes, although a few people did express feeling rather self-conscious at being taped. It should be noted that although I did give respondents the opportunity to withdraw at the beginning of the interview, it is possible that they may have felt uncomfortable saying they would prefer not to take part when I was actually there with them. However, I believe this is unlikely to have been the case because throughout the recruitment process there were a number of opportunities for respondents to either refuse to take part in the first instance, or to withdraw at a later stage.

Initially I asked respondents to tell me what had happened to them since they had first suspected that something was wrong with them, in effect I asked them to tell me their 'story'. I hoped that by doing this I would achieve a number of things: firstly, as Graham points out by asking respondents to talk in this way allows them to "mark out the territory in which intrusion is tolerated" (1984,107); secondly, it allowed me to gather a wealth of data which I may not otherwise have discovered had I used a more prescriptive interview schedule (Brannen,1988); and finally, this approach was a way of 'breaking the ice', by asking people to tell me their 'story' in their own way I felt that they relaxed a little, and felt more at ease. Telling 'stories' took different lengths of time. Some people spoke only for a few minutes, others for significantly longer. Katie

spoke to me for nearly 90 minutes without prompting during our first interview. It was also interesting to see how people told their story, often respondents who told me what had happened to them briefly and succinctly told me a very clinical story about referrals, operations, drugs, and hospital appointments - presumably a reflection of the many hours they will have spent in hospitals with different clinicians asking about their illness.

After respondents had finished telling me their story I asked them questions based on what they had said, perhaps asking them to explain in a little more detail about a certain point they had mentioned. It is at this point that I used a focused interview technique. This allowed me to explore different themes and issues in any order which seemed appropriate in that particular situation (Fielding,1993). I had a very brief interview 'guide', or *aide memoire*, which contained a list of issues I hoped to cover during the interview, these obviously changed over time given that the research was in the main inductive. As time progressed initial areas of interest were substituted with other more pertinent areas. A typical interview guide used after a few months of fieldwork, when I had conducted and analysed a number of interviews, included areas such as:

- Experience of care and treatment received
- Effect of diagnosis on self and family and friends
- Extent to which relationships had altered
- Changes which had occurred as a result of their illness
- Feeling and thoughts about illness and future
- Effect of illness on identity

Often respondents covered many of these topics as well as others I had not envisaged, to a lesser or greater extent, while they were telling their 'story'. If this was the case I often referred back to points they had made and asked them to clarify or elucidate a little more. However, if people had not mentioned specific issues which I was interested in I asked them more direct questions on these topics. Again, sometimes people would talk at significant length on the theme I had introduced, others gave only short answers.

Interviews lasted between 60 minutes and three hours, although I often spent longer with respondents explaining about the research before the interview, and staying to chat informally

afterwards, often over another coffee. After each interview I thanked respondents for their time and asked the majority of them (excluding the three people in remission) if they would be willing to take part in another interview in the future. Two respondents, Heather and Ruth, seemed unwilling to continue in their involvement. During their interviews they both told their 'stories' quickly, and did not elaborate in any great depth on questions asked subsequently. Given this it seemed inappropriate to ask them to take part in a second interview. The next day after each interview I wrote to respondents thanking them for their time and help, and reminding those who had agreed to do another interview that I would contact them again in about two months' time. I gave my university address and telephone number for people to contact me if they had any queries (although no-one did). After interviews I wrote brief notes, in my field diary or recorded comments on to the end of tapes to be transcribed after the interviews.

Approximately two months after the first interview I spoke to the HCT or DCC to see if they felt approaching individuals again would be appropriate. As a result of this process I did not contact two patients referred by the HCT, Margaret and Gail, as they were considered to be too ill, nor did I contact Karen who I had recruited via the DCC. I did not interview Karen a second time because I was informed that she had been upset by talking about her illness. I only discovered this fact some time after her first interview, and after consultation with the DCC staff I decided not to contact her again. Throughout my fieldwork the hospice also kept a list of the names of respondents who were taking part in my research and I was contacted if they were admitted on to the hospice ward, or if they died. I hoped that this would minimise the chances of me inadvertently telephoning the family of a respondent who had died, and subsequently upsetting them. Judy died shortly after her first interview, and a few days before her second interview Gaynor was admitted into the hospice, where she later died.

Once I had established that contacting people again was appropriate, I telephoned respondents again and asked them if they would still be prepared to be interviewed again. At this point Roger

asked me to call back because he was not feeling well that day. I called again in a few days time and he said that he really did not feel up to another interview. Of the remaining eight who were interviewed again, only two interviews were arranged and then had to be rescheduled when I telephoned the day before, both times because the respondents had been admitted into hospital. I used the second interview to establish to what extent events had changed, in terms of relationships, roles, emotions and general feelings of well-being; I also used this time to discuss emerging themes with respondents. After the second interview I again asked if I could contact them again in another two months, and I wrote a short note to each one again thanking them for their contribution. I did not ask one respondent, Gill, to be interviewed a third time, because she repeated herself quite extensively in the second interview. She appeared to find the fact she had got 'nothing new to say' quite frustrating, and consequently I felt it was unfair to ask her to take part again. I was able to interview Katie, Ann and Sarah a third time, but three other respondents, Rachel, Liz and Anna, died shortly after their second interview.

In summary, 30 interviews in total were conducted. Each respondent was interviewed once, eight respondents were interviewed a second time and three a third time. The different amount of interviews varied according to a number of criteria. Firstly, according to symptoms some respondents were too ill to be interviewed again, or died shortly after their interviews. Secondly, according to whether they were in 'remission'. I wanted to explore how experiences and feelings changed over time. Patients in remission told their stories at great length and in detail in retrospect, explaining how their feelings varied over time and in different circumstances. I felt, therefore, that it was not necessary to interview these respondents again. Thirdly, according to respondents' wishes, if individuals seemed either unwilling to continue their involvement, or 'uncomfortable, I did not approach them to be interviewed again.

Analysis

In some ways it seems inappropriate to highlight the analysis of interviews as a distinct phase in the research process, since for the majority of the fieldwork the processes of interviewing, transcribing and analysing occurred concurrently. However, it remains important to document the actual process I engaged with whilst analysing the data. The first stage of the analysis involved examining the interview data in detail, each interview was therefore transcribed verbatim to facilitate this process. The actual process of listening to the tapes over and over again and transcribing them helped me to become 'immersed' in the data. In addition to interview data I also referred to my own fieldnotes in which I often noted down immediate thoughts and feelings after each interview, these notes helped to structure my thoughts when first faced with pages of data.

I went through each interview transcript, systematically highlighting and noting particular phrases which appeared to be important, and which I hoped to reflect upon when conducting and analysing other interviews. As I analysed subsequent interviews I became engaged in the process of 'coding'. Coding involves attaching a particular label to data gathered during interviews, a code can be applied to a specific word, or more generally, a phrase or paragraph (Miles & Huberman,1994). In earlier interviews the codes I applied to the data were more tentative, and required further exploration and consideration. Initially a coded interview transcript would consist of different words and phrases. For example:

		PhD Interview:1610Ann
Catherine	When they didn't call it cancer did that make it easier at the beginning?	
Ann:	I think so, it's like what I said I don't call it cancer, cancer, it's Hodgkin's or the disease, yeah you're right, like if you've got lung cancer you've got cancer, and that's it, but it's nice that it's got a name, crazy! You just learn to cope so many people say to me you're strong, I don't know how you do that, what would you do? You can either curl up in a corner and feel sorry for yourself and die, because that's what'll happen, or you can get on with it and fight it. I've found a few times that if you give in to it, and start being really despondent, that it will get you, you do get poorly or poorlier	Not cancer - own name Label of cancer Control Cancer can take over - fighting

Catherine	You've found that from your own experience?	
Ann:	Yeah, absolutely, and you need to be kicked up the backside to get yourself positive again, and it really is true, I mean you can see people in hospital giving up. I did it myself, when I didn't think I was going to make it and that was it bye bye, and for about three days I just lay there practically in a coma, and it was true. It wasn't until Geoff had a good chat to me and said, "What are you doing?" that I started to perk up again. But it took me a good week to perk up again, and the Monday after the doctor came round and I was sitting up smiling again, and it's all up here, in your head.	Positive thinking Control -mental
Catherine	But you have to work hard at it?	Hard work - need to fight Cancer can win
Ann	You do, yes, because it will beat you, I don't know how, but there's certainly something in the old mind up here.	

Each interview was coded initially, then in the light of subsequent interviews it was re-examined and further notes made. The process of 'constant comparative analysis' (Glaser,1966) within and between interviews meant that as time progressed certain 'core categories' became evident (Strauss,1987). Further, the continuous process of data collection and analysis allowed me to explore the appropriateness of certain emergent themes, and this meant that as time progressed certain categories became 'theoretically saturated' (Glaser & Strauss,1967). Within the identified 'core categories' certain related sub-categories existed. For example the core category of 'identity' had other related sub categories:

IDENTITY				
⇓	⇓	⇓	⇓	⇓
Images of cancer	Invasion of cancer	Changes in relationships	Cancer and dying as stigma	Dying as outsiders

Broadly speaking the core categories generated from the interviews are central to each data chapter (Chapters 4-7), within each chapter the sub-categories which are related to each of these core-categories are also discussed and explored.

Finally I collected all the data pertaining to one particular category and filed them together. Index cards with quotes from different people were constructed in order to facilitate the 'writing up' process. Such cards contain the following kind of information:

Ref: Treatment/Chemo 10	
But it was the chemotherapy, when it finished I thought what do I do now, what happens to me now what happens if it's not been killed, and I'm left now what happens?	1011Edna3[4]
Am I going to lose me hair, am I going to feel deathly?	2011Pat
It was quite funny because you had a bag of saline then you'd have your bag of chemo and that's a black covered bag, obviously because of the light, but I think oh why don't you put a skull and cross bone on it?	43Katie3
I think the chemo I'm coming to end of my treatment now and I'm thinking, your body's at rock bottom, it must be, because the chemotherapy just the, you know, the drugs they pump into you they're all poison toxins, and I've been told by the nurses it's just playing havoc with your body	291Karen7

Leaving the field

The fieldwork period lasted just over a year, in September 1996 I made the decision to stop interviewing: firstly, because I felt I had collected sufficient data to support the theoretical points that had emerged from the data; secondly, because of time constraints; and thirdly, on a more personal level I felt that I had reached a point whereby I needed to withdraw from the field (at the very least for a short time). It is important to recognise that the interviewing process is physically and emotionally draining for the researcher as well as the researched. At the end of the fieldwork three respondents were still believed to be in 'remission', five were living with their advanced cancer and eleven respondents had died. After ending this stage I wrote to all my remaining respondents explaining that the fieldwork had now come to an end and I would not be contacting them again, but I thanked them all individually for their help and time. I also wrote to the hospice

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[4] The first digits symbolise the date of the interview and the final number is the page from which each quote was taken

staff who had been instrumental in recruiting and helping me throughout the research, thanking them for all their time and help. I still remain in contact with the DCC staff and HCT and I see some respondents when I visit the DCC.

The hospice has continued to keep me informed about my respondents and since completing my fieldwork Rebecca, Roz[5], Katie, Gill, and Ruth have died. Pat, who described herself in 'remission' when I interviewed her, has now had a bone marrow transplant and is making good progress. Ann's condition continues to fluctuate, and she is currently having chemotherapy again. Edna remains clear of cancer, but continues to worry about what may occur in the future.

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[5] In her interview Roz had told me that she was in 'remission'.

Chapter 3

Research Issues and Dilemmas

In this second chapter concerned with methods and methodology I concentrate on theoretical and

ethical issues which are pertinent to my study. I do not necessarily discuss methodology or ethical

issues separately as many of the factors relating to either are often intimately bound up with the

other. The aim of the study on which this thesis is based was to explore the experiences of living

with a terminal illness from the individual's perspective, and to make their views and experiences

central to both the actual research process, and its subsequent written format. This is a qualitative

study, as such it does not seek to make empirical inferences from a statistically representative

sample; rather it seeks to develop theoretical inferences from the data, and provide a sociological

analytical account of the experiences of living with a terminal illness.

> ....the essential point about the basis of making inference from case material; [is] that
> the extrapolation is in fact based on the validity of the analysis rather than the
> representativeness of the events. (Mitchell,1983,190)

Mitchell (1983) discusses the grounds on which generalisation can be made from case study

material, relating this to Znaniecki's (1934) discussion of analytical induction Theoretical

inferences, Mitchell argues, can be drawn by making relevant and justified connections, based on

systematic and detailed analysis, between empirical data and theory.

> The validity of the extrapolation depends not on the typicality or representativeness
> of the case but upon the cogency of the theoretical reasoning. In terms of this
> argument case studies may be used analytically....only if they are inbedded in an
> appropriate theoretical framework. (Mitchell,1983,207)

The emphasis is on the appropriateness of the theoretical inferences, which means that there is a

need to ensure that "our analysis is unassailable." (Mitchell,1983,200). To what extent any

analysis can claim to be unassailable is open to debate, however, I feel that what is imperative is

that analysis should always seek to be detailed, reflexive and systematic in nature, thus ensuring

that any inference made can be justified. As I discuss later, the approach I used in data gathering

and analysis involved a combination of techniques. At times I used an inductive approach and

allowed themes to develop from the interview data, however, at other times deduction was important. For example I considered the common themes which emerged from the interview data in relation to relevant sociological literature; as tentative theoretical connections were made I used subsequent interviews to explore their validity. I believe this process has allowed me to develop an appropriate theoretical framework which remains firmly rooted in the experiences of respondents.

Theoretical Perspectives and Influences

This study's methodology is essentially interpretative in nature, and is influenced by a number of different traditions and approaches. The aim throughout was to understand the social world of those who are terminally ill, as they themselves perceive it, by gathering experiential data. This aim would seem to fit closely with Weber's (1922) concept of *Verstehen* which seeks to interpret actions by considering their subjective meaning. Verstehen involves the researcher seeking to develop an empathetic understanding of the social world of respondents as they themselves perceive it. My study also reflects some of the principles of symbolic interactionists:

> Basically, interactionists provide an interpretative view of sociology which puts emphasis on understanding the actions of participants on the basis of their active experience of the world and the ways in which their actions arise from and reflect back on experience. (Burgess,1984,3)

In subsequent chapters I illustrate the ways in which this is pertinent to my research by grounding any discussion firmly within the experiences of respondents. The data and discussion presented here reflects their perceptions and their experiences, whether these were accurate or not is not a concern, because, as Thomas and Thomas argue: "If men define situations as real, they are real in their consequences"(1928,572 cited in Ritzer,1996,195). What people believe to be reality, whether it is in fact an accurate interpretation or not, affects what they do and how they react in certain situations.

When using interview data it is important to note that the interview is also, as Ribbens points out, merely "a particular type of social encounter" (1989,579), in this situation researcher and

researched will choose which pieces of information to divulge and which to withhold. In everyday interaction all individuals engage in some form of 'impression management' (Goffman,1990a), we consider the costs and benefits of revealing certain pieces of information about ourselves in different situations. I would argue that within an interview there are certain issues which will always remain hidden from a researcher for whatever reason. For example, a respondent may not want to talk about something, because it is too painful, too embarrassing or merely because they think it has no direct bearing on the interview. This does not invalidate the data particularly given that the aim is to highlight emerging themes and issues which are common to respondent's accounts and relate them to other sociological theory.

> What is important is not the content of the case study as such but the use to which the data are put to support theoretical conclusions. (Mitchell,1983,191)

By attempting to make respondents' views central there was a need to ensure that any theory related to the research was pertinent to their accounts. Consequently I sought to develop a theory from the actual experiences of respondents. Such an approach is usually associated with Glaser and Strauss' "Grounded Theory", in which they advocate the aim is "the discovery of theory from data." (1967,1). Strauss and Corbin (1990) argue that "grounded theory" is not a specific method or technique, but rather it is a style of doing qualitative analysis which has a number of distinct features, the most important being that it seeks to generate and formulate theory from empirical data.

> A *grounded theory* is one that is inductively derived from the study of the phenomenon it represents. That is, it is discovered, developed and provisionally verified through systematic data collection and analysis of the data pertaining to the phenomenon. Therefore data collection, analysis and theory stand in reciprocal relationship with each other. One does not begin with a theory, then prove it. Rather one begins with an area of study and what is relevant to that area is allowed to emerge. (Strauss & Corbin,1990,23)

Grounded Theory is frequently referred to within many methodology texts (e.g. Burgess,1984; Hammersley,1989,1992; Layder,1993; Silverman,1993), and it is claimed to be one of the guiding influences of some computer software programmes designed to analyse qualitative data (Bryman

& Burgess,1994). Implicit from such widespread reference is that Glaser and Strauss' Grounded

Theory has provided a significant contribution to qualitative methods and methodology. However,

in reality, it seems that the term 'Grounded Theory' is frequently used in research:

> .... to denote an approach to data analysis in which theory has emerged from the data.
> Rarely is there a genuine interweaving of data collection and theorising of the kind
> advocated by Glaser and Strauss. (Bryman & Burgess,1994,6)

> .... as a general indicator of the desirability of making theory from data, rather than a
> guide to a method of handling data. (Richards & Richards,1994,149)

Like other qualitative researchers I too have only broadly adopted the methods and basic premises

governing grounded theory. I was particularly drawn to the inductive nature of Grounded Theory,

the notion that theory should be rooted in empirical data, and the process of 'constant comparative

analysis'.[1]

> The constant comparative method can be described in four stages: (1) comparing
> incidents applicable to each category, (2) integrating categories and their properties,
> (3) delimiting the theory, and (4) writing the theory. Although this process is a
> continuous growth process - each stage after a time transforms itself into the next -
> previous stages remain in operation throughout the analysis and provide continuous
> development to the following stage until the analysis is terminated.
> (Glaser,1965,439)

The flexibility Glaser and Strauss advocate when conducting research also seemed appropriate to

my research, if I was to avoid imposing a prescriptive framework on the research. However, I did

not follow or employ all the techniques and procedures advocated in their work therefore it is

inappropriate to apply the label "Grounded Theory" to this study, a more accurate description

would be to say that in my research has been informed by the principles of Grounded Theory.

Initially I began my research by becoming familiar with the literature related to the area, this

informed some of the first interviews in terms of the areas I thought may be interesting to explore.

Data collection and analysis occurred concurrently, this meant that interviews were transcribed

verbatim and analysed as soon as possible. As illustrated in the last chapter, analysis involved

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[1] The 'constant comparative method' was first discussed in Glaser's (1966) paper "The constant
comparative method of qualitative analysis". He states "This paper developed out ot the problems of
analysis arising during the study of terminal care in hospitals; particularly the interaction of staff and dying
patients." The concept was later included within Glaser and Strauss' (1967) more detailed discussion in *The
Discovery of Grounded Theory*

coding the interview transcripts to highlight emerging themes and issues. As the research progressed issues which emerged from earlier interviews helped inform subsequent ones, although these themes were not used prescriptively if new issues were mentioned, these were explored in the same way. What began to occur was that it was possible to identify certain common features between accounts, as Tait points out:

> R's experience was unique to her and yet it contained numerous facets common to others. (1990,173)

As the data gathering continued these common categories became well established in the analysis as respondents discussed or alluded to them time and again. These categories then informed later interviews and it began to be possible to start developing a theoretical framework from the accounts. In broad terms this process reflects the principles of Grounded Theory in that I did seek to generate theory from the data, and I also engaged in the process of constant comparative analysis by comparing emergent themes between and within interviews.

The approach I used differs from Grounded Theory in that although it was inductive, to the extent that themes were allowed to emerge from the data, inform future interviews and shape the written presentation of the research; deduction was also important. It would be naive, I believe, to claim that what I have read prior and subsequent to the fieldwork has not had some bearing. As Stanley and Wise argue "researchers cannot have 'empty heads' in the way inductivism proposes" (1990,22). I feel it is unclear in Glaser and Strauss' discussion where 'theoretical sensitivity' ends and a process of 'deduction' begins and, for this reason, I feel it is inappropriate to apply this label to this part of the research process. Initial reading of the literature alerted me to debates and discussions within different disciplines. Although I would not claim to have had *a priori* categories, there were certain issues I was interested in exploring during interviews as a result of my reading. For example, individuals' experiences of the care they received and the effect of their diagnosis on their relationships with significant others. Some of the areas in which I was originally interested, for example the importance of religious or spiritual beliefs in the latter stages of life, were rejected early on in the research when respondents never mentioned these

things without prompting, and even then it became apparent that these were not necessarily issues which were particularly relevant.

Towards the end of the fieldwork period I began connecting the analysed data with relevant sociological literature. In this way I was able to give labels such as "stigma" and "emotional work" to some of the experiences respondents discussed, despite the fact they themselves were unlikely to use these terms. By considering the literature relating to stigma, I returned to the data and was able to conduct a more detailed examination of the data in terms of identity and its management. By adopting both an inductive and deductive approach to data gathering and data analysis, I feel that I have maintained the centrality of respondents' experiences, and provided a sociological account of those experiences.

The small sections of quotes from interview data which I use throughout my thesis have not just been picked for 'convenience', but I believe they provide an insight into each particular interview as a whole. Quotes were selected on the basis that they reflected or summarised most accurately the experiences of a number of people. This accounts in part for why some people have been quoted more than others, in that their words often seemed to most accurately represent a number of different respondents' experiences or feelings. Further, although I have used quotes from each respondent, given the variation in the number of interviews conducted with each person it is not surprising that some respondents are quoted more frequently than others. Finally, it is important to note that quotes were not selected merely to support the point I was trying to make, rather I took care to seek out and use 'deviant' quotes which illustrate a different perspective or experience.

Personal issues and dilemmas

An awareness of one's own role and influence in the research process has been an area of concern and debate amongst social scientists for some time. Weber (1949) stressed the importance of

researchers recognising their own ideals and values, and being aware of the implication they have for their research. 'Naturalistic' sociology, in particular, has always emphasised the importance of the interaction between researchers and their respondents. Despite this, traditionally within social science research there has been a tendency to feel that research has been carried out by 'non-people' (Bell & Newby,1977).

> The researcher is a 'variable' in the interview process in several ways. Researchers bring their own life experience to their research and they structure what the research is about..... interviewing itself is an interactive process. The [respondents'] accounts were the result of their interaction with me. The particular occasion of telling their stories was my intervention as a researcher. Moreover, their stories were also slanted by their perceptions of me and the research. (Edwards,1993,185)

Similarly, Strauss (1987) asserts that researchers need to be aware of their own role in developing an emerging theory.[2] Developing this argument further, Becker argues that it is not possible "to do research that is uncontaminated by personal and political sympathies" (1967,239); researchers do not work in a vacuum (McRobbie,1982,48).

> The point is that minimising the influence of the researcher is not the only, *or always even a prime*, consideration. Assuming we understand how the presence of the researcher may have shaped the data we can interpret the latter accordingly and it can provide important insights, allowing us to develop or test elements of the emerging analysis. (Hammersley & Atkinson,1995,131)

Feminist researchers, Stanley and Wise (1983,1993), advocate the need for researchers to locate themselves and their emotions within the written account of their research.

> ...the basis of all research is a relationship, this necessarily involves the presence of the researcher *as a person*. Personhood cannot be left out of the research process. And so we insist that it must be capitalised upon, it must be made full use of.
> (Stanley & Wise,1983,162).

Feminist researchers in particular have tried to address in some detail the significance of the role of the researcher within the research process, and the related issue of power within the research process. I feel that my reading in this area has informed the account I present below. In it I draw on some of the debates and dilemmas raised by feminists when I consider my own role, research

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[2] It should be noted, however, that there is an implication in Glaser and Strauss' (1967) work that the influence of the researcher will be minimised/eradicated through the application of the procedures they advocate.

relationships, and the personal issues and dilemmas I encountered both during and after the fieldwork period.

I feel that it is important to locate myself within the research: firstly, because for methodological reasons who I am is likely to have had a significant impact on the data I collected; secondly, ethically I feel it important to discuss my status within the research process; and thirdly, on a more practical level, there is very little written about what it is actually like to do research within a palliative care environment (Davies *et al*,1995). I began the fieldwork having little or no personal experience of cancer, dying or hospices. My grandfather died unexpectedly some time ago as a result of an accident, but his dying took place in an Intensive Therapy Unit, a very different environment to a hospice. Despite this lack of personal experience I had developed an interest in long term chronic and terminal illnesses and their effects on people's lives. This research developed from that interest and my desire to explore what it is like to live with a terminal illness. Further, I wanted to make the views and experiences of those individuals living with a terminal condition central to the research. Before beginning to consider my own role within the research process, it should be noted that Lofland argues that researchers only ever discuss "the second worst things that happened," and further, that "we delude ourselves if we expect very many field workers actually to 'tell all' in print" (1971,132-3). Given this it seems likely that the degree of honesty researchers incorporate into their work will vary between different written accounts, and for different reasons. What I discuss below, similarly, does not include reflections on everything for a variety of practical, ethical and personal reasons.

Respondents form their own opinions about the researcher and the research, which in turn inform the way they react in the interview and interact with the researcher. It has been argued that respondents engage in a process of 'placing' the researcher, in terms of age, race, class, gender, comparing the similarities and differences between them (Burgess,1984). Cannon argues that:

> ...the fact that I was working in the hospital endowed me with such legitimacy, at least in the eyes of the women I was interviewing. (1992,151)

Similarly, I felt some of the difficulties which may have been encountered in gaining the confidence of respondents were alleviated by the fact that they perceived me to be associated with an organisation they trusted. For me this was of invaluable help, however, it should also be considered how it may be relatively easy to exploit some vulnerable people because of the trust they place in a particular organisation and those associated with it. It may also have been the case because of my association with a university respondents viewed me as being some kind of 'expert'. If this was the case my 'expert' status was unique because, unlike doctors or HC Sisters, I did not have any professional or personal involvement with individuals outside the interview environment. Finch (1984) suggests that being 'placed' as a woman by a female respondent suggests a shared structural experience which becomes central to the interview process. However, Ribbens (1989) argues even if researcher and researched do share the same gender differences may still exist in terms of age, class, ethnicity, or professional status. In terms of this research I shared the same ethnicity with all my respondents and the same gender with the majority. However, there was often an age difference between us and at times my social background was different to those I interviewed. More importantly one fundamental difference was apparent throughout, I was healthy.

If I was to gain in-depth accounts of respondents' experiences a relationship of trust needed to be developed (Cannon,1989,1992). To establish this kind of relationship we both needed to be prepared to invest some time and effort. Oakley (1981) advocates the need for a 'non-hierarchical' relationship between researcher and researched if exploitation is to be avoided. Although I hoped I would not exploit respondents in any way, I was aware of the difficulties inherent in aiming to establish a 'non-hierarchical' relationship.

> In an interview situation which seeks to be egalitarian and involves listening with care and concern the distinction between a research relationship and friendship may become blurred. And when a woman then talks about very painful aspects of her life to another who will eventually walk away, there may be potential for harm. (Cotterill,1992,599)

I did not seek to become respondents' friends, although naturally with some I developed a greater rapport than with others. Despite this I would not refer to myself as a 'friend', nor do I think my respondents would see me as such. Finch (1984) discusses the role of a researcher in terms of being a 'sympathetic listener', Cotterill and Letherby (1994) question this view and suggest that many respondents do not need anyone to adopt this kind of role because they have their own social networks which may fulfil this need. However, I feel that on occasions I did act as a 'sympathetic listener' because at times respondents said that they found it difficult to speak to friends and family about certain topics. Despite this, it should be noted that I was not the only person respondents could talk to, often they developed other networks outside the home, for example with other patients or with a professional counsellor. Brannen believed that her respondents used the interview experience "as a catharsis" (1988,558); in terms of the interviews I conducted I feel reluctant to subscribe to this view. I agree that some respondents did appear to appreciate the opportunity to talk about their illness and its effects to someone who was neither close to them emotionally, nor involved with their care, but in no way did the interview aim to be anything more than a means of gathering data in as sensitive a way as possible. There is, it would seem, sometimes an implication that respondents need something back from an interview:

> ....why should we assume that we can actually *do* anything for *them*? Is this not an immensely patronising stance? How can *we* assume *they* need anything done for them in the first place? Or conversely that we have anything real to offer them? (McRobbie,1982,52 - original emphasis)

I am not a counsellor, and throughout my research I have felt uncomfortable with any suggestion that interviews had a hidden agenda to be therapeutic, were used as such, or indeed that respondents should even need some form of therapy. The term I feel most comfortable with to describe my role in the research process is that of a 'friendly stranger' (Cotterill,1992).

> The 'friendly stranger' unlike a friend, does not exercise social control over respondents because the relationship exists for the purpose of the research and is terminated when the interviews are complete. (Cotterill & Letherby,1994,120)

Being a 'friendly stranger' became problematic for me when certain respondents died, because some deaths affected me more than others. As a 'friendly stranger' I had no particularly significant role in my respondents' lives, and this seemed to sit rather incongruously with the

emotions I felt at times. It seemed that I had no 'right' to feel any long term sense of grief, loss or sadness. I also experienced a sense of guilt when some respondents died, and their deaths did not have the same emotional effects on me as those of others, although I understand individual personalities dictated the kinds of relationships which developed between myself and different individuals. The effects of some deaths are still apparent now in different ways, and I feel the fieldwork in general will have some long-term effects on me.

> It would be over dramatic to say that it 'changed my life' (although it has a lasting effect) but it certainly 'took over' my life in terms of emotional involvement in ways I was not prepared for, and taught me a number of 'extra-curricular' lessons about life and death, pain and endurance and human relationships. (Cannon,1992,180)

It is important when considering the research process to also reflect on the issue of power. Some writers argue that it is the researcher who is powerful by virtue of their social position, which is presumed to be superior to that of respondents (e.g. Cornwell,1984; McRobbie,1982). The researcher sets the agenda, takes the data away, analyses it and writes about the research. However, respondents are not without their influence, most obviously, they can choose whether to take part in the first instance, whether to not answer questions or to omit details (Ribbens,1989). Cotterill (1992) in her study of mothers-in-law and daughters-in-law felt that power was weighted towards her respondents at times. Firstly, some of these women came from similar social backgrounds to her and did not feel intimidated by being interviewed; and secondly, she felt vulnerable at times because she was younger than some of these women. Many of the group I interviewed were older than me, I was often closer to the ages of their children than them, and at times I also felt uneasy. These feelings varied between individuals. With some people I was more conscious of my age than with others, equally I was more aware of this issue earlier in my fieldwork when I felt less confident in my role. Transcribing the taped interviews also brought their own issues and dilemmas, most notably a few months into the fieldwork I was asked by a woman I had interviewed to edit her interviews, and produce a tape for her family to give to them after her death. I agreed to this request, although I had never really anticipated the emotional costs this would involve for me personally. Becoming involved in the grieving process of a family I had

never met was extremely difficult, and making a tape for them made me feel vulnerable. In some ways I found myself in an unusual paradox, on the one hand I had the 'power' effectively to edit the tapes in any way I felt fit, but equally I felt powerless in terms of the consequences this action would have. When the woman's husband came to pick up the tape from my home, as he had insisted, I was left feeling extremely unnerved.

Ultimately, power rests with me because I have now left the field and analysed the data (Ribbens,1989). I am now presenting that information in the form of a sociological analysis, in a format which is not readily available to everyone, and even if it was, many of my respondents are no longer alive to express any dissatisfaction. Some family members have subsequently expressed an interest, but how and what I present to them in a report is again ultimately my responsibility. It seems likely therefore that the balance of power varies throughout the research process. To talk then of power being vested in one particular half of the interview relationship seems to be misleading, because power within the research setting is often much more problematic and complex; power changes within interviews, over time, between different individuals and in different circumstances.

During this research I have been involved in my own emotional work (Hochschild,1983). Emotional work, as already discussed, is the effort required to deal with people's feelings within the private sphere, it is a social process in which the regulation of emotions is a central concern. My emotional work during the fieldwork period required me to at times to deal with situations which were emotionally difficult for respondents, and difficult for me. During her second interview Anna asked me if she was, "Doing the right thing?" Subsequently I spent time reassuring her that I felt that there was no right way to do things, just ways which feel right to individuals. Sometimes the emotional work was just sitting and listening to individuals' stories, at other times it was managing my own emotions when I heard things which made me angry, or were extremely distressing. Emotional work was also the hugs, or the holding of hands when

individuals were unable to speak, silence then was emotional work. Like Cannon (1989), at times during the research process, I felt thoroughly useless, wishing I could do something to help, but realising in effect there was nothing I could do, at times the silences and tears were hard to bear. Learning to accept respondents' emotions, and do nothing but listen, was one of the more difficult parts of my research, was I really, as McRobbie wrote, merely "holidaying on other people's misery?"(1985,55). Since the fieldwork has ended my emotional work has continued in differing degrees at different times. Like Copp (1996) I found that the deaths of respondents at times provoked grief and sadness. Re-reading the transcripts of those who are now dead brings with it its own kind of emotional work, in terms of remembering and reflecting.

Emotional work is an integral part of much social research, and at times it can be extremely demanding and draining (Young & Lee,1996). It was something I had never really thought about to any significant extent before entering the field. It is not possible I would argue for any researcher to spend any prolonged length of time involved in any research without it having some effect on their own lives. During the fieldwork I spent hours in people's homes listening to their stories, talking about their lives, and answering any of their questions about my life and the research. I then took the tapes and spent many hours and days transcribing them in my home. Trying to deal with both respondents' emotions and my own became more difficult as time progressed, and doing this for a prolonged period of time certainly had its effects. There were times when I could not face listening to another interview. Research of any nature is often a lonely experience for the researcher, but these feelings may be compounded when extremely emotive or 'sensitive' issues are being studied. Lee discusses the problem of 'contagion' faced by researchers.

> Where deviant groups or individuals are being studied research can become problematic for the researcher. This seems to be true in particular for researchers on human sexuality.... researchers may find their work trivialised or treated in a joking manner. (1993,9)

The group I was studying may not necessarily automatically be labelled as 'deviant' (except perhaps to the extent they were all dying 'prematurely'), but the comments made by friends and

associates leaves me in little doubt, that some people regard me in this way. After all why should anyone want to do research involved with anything to do with *dying*? Another pertinent issue here is the lack of support often available to researchers working alone in any area, but particularly one which places so many emotional demands on the researcher (Payne & Westwell,1994). As Brannen points out:

> Having sat for several hours at a time in people's homes listening to their stories and to their distress I have often thought that no psychiatrist or psychotherapist would work (or be allowed to work) under these conditions....Long sessions are exhausting and emotionally draining for both parties. (1988,562)

She goes on to argue that "confiding is normally a reciprocal process" (562). Other professionals whose work involves listening to others have their own support, researchers, however, are often left to find their own sources of support, usually other drained researchers, to whom they can 'debrief'. To those colleagues and friends who listened to me during my fieldwork, and after, I remain extremely grateful.

Reflections on participation and respondents' accounts

As has already been stated this is a qualitative study which does not seek to be representative, however, I feel it may be of some value to consider those who did take part. [3] All my respondents had been referred to LOROS for one of its services. In many ways the study group was self-selecting, although everyone was approached initially by either the Home Care Team (HCT) or myself, it was not compulsory to take part, individuals chose whether they wanted to be involved or not. So why did people agree to take part? It may be of some benefit to try to speculate on some of their reasons:

> I placed value on a status, that of cancer patient, which was generally considered to be a negative one. Their part in the research may have given a sense of usefulness at a time when this was being diminished in other respects. (Cannon,1993,173)

Like Cannon, I feel that for some respondents being involved in the research may have been a means of reaffirming their own social worth or identity, because despite the fact they often could no longer do everything they used to, they were still valued and important. Respondents did not

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[3] A more detailed discussion of the recruiting process is discussed in Chapter 2.

expect anything back in return for taking part in the research (McRobbie,1982), although it was frequently mentioned that they hoped that the research might help others in a similar situation. Anna said, "Even if it just helps you get your PhD that's enough." Roger had his own slightly different motive for taking part, he obviously enjoyed being able to talk about his illness in an environment where it was positively encouraged, he said,

> I'm so fascinated by the whole thing you know. There are times when I can't stop myself talking about it, and sometimes I say to myself, woah, you know, you might be upsetting someone Roger.

No doubt individuals had their own reasons and motives for taking part, perhaps for some my association with the hospice (despite the fact I emphasised I was from Coventry University) meant that they felt they were helping the organisation in some way. With this issue in mind, I have maintained close contact with the hospice both throughout my research, and since it has ended.

It may be argued that my study group has certain limitations. Firstly, the study group comprised 18 women and 1 man aged 27 to 67, therefore it may seem reasonable to suggest that this study may be both age and gender specific in terms of the experiences of dying it discusses. Further, all respondents had been diagnosed with cancer, therefore it may be assumed that the accounts and discussions which follow are not necessarily relevant to individuals dying with other chronic or acute illnesses. Using interviews to gather data, meant that it was necessary for respondents to be able to speak with relative ease, clearly this precluded patients with other chronic terminal conditions, such as Motor Neurone Disease, which may make speech difficult. Five people when approached either refused immediately to take part, or withdrew before the interview took place. Implicit from this is that this study lacks the contribution of those who are either unwilling, or feel uncomfortable, talking about their illness per se, or talking to a stranger about their illness. Finally, obviously there are those individuals who were never approached, those who were too ill, or who were not expected to live for 6 months.

However, having noted the above it is important to state what inferences I believe can by drawn from this study. Firstly, the fact that the study is not statistically representative does not affect its validity. As has already been discussed the purpose of this research was to develop appropriate *theoretical* rather than *empirical* inferences from the data. Mitchell argues that:

> The very particularity of the case study, located as it is in some social setting, however, can be turned to good advantages; it can provide the opportunity to demonstrate the positive role of exceptions to generalisation as a means of deepening our understanding of social processes. (1983,206)

Although the individuals involved in this research were all under 67, predominantly female and diagnosed with advanced cancer, there are certain theoretical generalisations which can be made which are applicable to a much wider population. Further, although this research is ostensibly about individuals who are living with a terminal illness, living with the knowledge that they are dying, does not mean that theoretical inferences can not be applied more broadly. For example, any discussion on the way that individuals construct and manage their identity is also relevant to other groups with different diagnoses, and to those who are not terminally ill.

Interviewing: ethical and methodological issues

As already discussed, there is considerable academic debate about whether dying and death are taboo, and what is actually meant by the term. Within contemporary society, however, dying and death are often perceived to be topics which at the extreme should not be mentioned at all in conversation, or in more weaker instances people just feel uncomfortable talking about them (Walter,1991).

> Traditionally in Western societies, the back-regions associated with sex, reproduction and death have been marked off by strong physical, symbolic and moral boundaries. (Lee,1993,20)

Respondents also seemed to be aware of this, as Edna put it:

> If you talk about death with other people everything goes quiet, it's like a taboo subject, nobody thinks about death, or wants to talk about death, we all think we're going to live forever.

Given that respondents perceived that others were uneasy in their company I feel it is reasonable to define dying and death as 'sensitive' topics:

....a sensitive topic is one that potentially poses for those involved a substantial threat, the emergence of which renders problematic for the researcher and/or the researched the collection, holding and/or dissemination of research data. (Lee & Renzetti,1993,5)

Talking about a terminal illness and dying and death, like discussing bereavement, is 'threatening', in that it is potentially upsetting and stressful for individuals to reflect and talk about these issues (Lee,1993). However, Lee and Renzetti (1993) point out that there is a difficulty in using the phrase 'sensitive' topic, because it may be the case that what is perceived to be a 'sensitive' topic by one group, or individual, is not necessarily perceived as such by others. This variation between groups and individuals makes the application of the label 'sensitive' problematic, because it could be argued that in essence that any area of interest in social research could be perceived to be a 'sensitive' topic. This point is certainly pertinent to my own research where it was clear that respondents had different attitudes towards talking about their illness, dying and death. In the first instance there were those who refused to take part in the research at all, perhaps because for them any discussion of this kind, with anybody, or just with someone they did not know, was difficult and perhaps inappropriate; the subject was too 'sensitive'. Other respondents found talking about their illness relatively easy, but found any allusion to death difficult to discuss. However, some spent many hours discussing plans they had made for their funerals, their wills, what kind of death they hoped for, and how they thought their family would cope after their death. To these individuals, it would seem, discussions of this kind were not a 'sensitive' topic during our interviews, however, some spoke about how under different circumstances, for example with friends and family, discussions of this nature were much more problematic. This suggests the label 'sensitive' is also locationally specific, in that, individuals may interpret different topics as 'sensitive' in different situations.

The method used combined a 'life-history' approach with a focused interview. Given that I wanted to learn about individual's experiences and perceptions of their illness, I hoped the combination of these methods would allow me to collect my data in as non-prescriptive a way as possible. As I discussed in the last chapter each respondent was interviewed at least once, with a

sub-group being interviewed a second or third time. I adopted some of the principles of the 'life history' method in the hope that this would make respondents feel more comfortable.

> .....in the sociological life history [the aim is] to grasp the ways in which a particular person constructs and makes sense of his or her life at a given moment.... the sociologist's goal is in a sense merely concerned with getting at the way a person sees his or her life history at the moment of the interview. (Plummer,1983,105)

The use of a focused interview seemed appropriate given that:

> Many topics - especially those of a sensitive kind - remain ill-suited to study by means of the survey. In these circumstances, a preference has been voiced for the use of the 'unstructured' or 'depth' interview. (Lee, 1993,101-102)

There is some debate within the literature about whether single, one-off interviews, or repeated interviews are more appropriate when trying to gather data of an intimate and personal kind. Brannen (1988) believes that when researching a 'sensitive' topic a one off interview may be more appropriate as this ensures that the respondent has no fear of meeting the researcher again, and the desire for anonymity and secrecy is fulfilled. Others however, advocate the use of repeated interviews (e.g. Laslett & Rapaport,1975; Oakley,1981; Cornwell,1984). Laslett and Rapport (1975) argue that in early interviews respondents are keen to present a 'best face', or in Cornwell's (1984) terms a 'public' account, to the researcher. In subsequent interviews, as the research relationship develops and trust is established, Cornwell argues that 'private' accounts will be given:

> Public accounts are sets of meaning in common social currency that reproduce and legitimate the assumptions people take for granted about the nature of social reality. There is a public account of most subjects which occur with regularity in conversation, the point being that in sticking to the public account of whatever it is they are discussing...... the person doing the talking can be sure that whatever they say will be acceptable to other people....Private accounts spring directly from personal experience and from the thoughts and feelings accompanying it. (1984,15-16)

This research, however, combined both single and repeated interviews, out of necessity rather than choice because of the nature of the research. Single interviews varied a great deal in nature sometimes, people spoke quite openly and at length about their illness and its effects, others gave more restrained and 'public' accounts requiring more questions to be asked in order to explore

points in more depth. Only two respondents were not contacted a second time, because they seemed uncomfortable when I suggested another interview in the future. This may be because, as Brannen (1985) points out, they felt they could say things during the interview without any fear of meeting me again. Another reason may have been that they had divulged all the information they were prepared to give to a stranger, and any subsequent intrusion on my part would have been unacceptable. Other respondents who were only interviewed once, were not contacted solely because they were not considered well enough to take part in an interview by hospice staff, not because they had made any suggestion that they would be unwilling to participate in the future. With regard to repeated interviews, on some occasions it became clear that in the second or third individuals gave *more detailed descriptions and insights, more 'private' accounts, without the* prompting they may have needed in the first instance when they appeared to give more 'public' accounts. However, it should be noted that some respondents spoke quite 'openly' throughout their interviews, and I was never aware of any change in the kind of information they gave or in any discrepancies or changes in the accounts they gave.

Given the differing experiences of my study group I am reluctant to say categorically that either approach would have been ideal for all respondents. I feel there is a need for flexibility when considering the method to be used, because individuals will respond to different approaches in various ways. The nature of this research meant that it would not have been practical to be too prescriptive about the number of interviews conducted with each respondent. I am also unsure to what extent the term 'private' account is entirely accurate, this suggests that there is a given 'truth' which can be uncovered. As I discussed earlier I believe, however, that there are things which will always remain hidden from a researcher. This is not, I feel, unreasonable, nor does it invalidate the nature of the data particularly given the fact common themes and experiences did emerge from the analysis of the data. However, at other times I felt that respondents sometimes talked about things with me in a way they would not necessarily have done with family and friends. As Ann put it:

> I can quite happily sit there and chat and laugh and tell her [an acquaintance at the hospital] all about myself, and listen to her tell me all about herself, and it doesn't bother me. But when it comes to somebody who I'm really close to, who I really love, or who I know loves me I can't do it. I can talk to you, cos I don't love you, you're outside the family, but I just can't talk to the family.

To Ann, and probably to others, I was indeed just a 'friendly stranger'. She felt able to talk to me about certain emotive issues because she felt that they would not hurt me. Equally, presumably there were things respondents chose not to tell me, again precisely because of this status of a 'stranger', which meant that there were things I should not, or did not need to, know. Again as I stated earlier it is important to be aware that in everyday we all engage in some form of 'impression management' (Goffman,1990a), and an interview is merely a particular situation in which we engage in some form of interaction with another person.

Prior to agreeing to take part in the research each respondent had received a letter explaining the aims of my research and what the interview would entail. In this letter I tried to explain that I wanted the interview to be as relaxed as possible, and that I hoped it would be more like a 'conversation' than a stereotypical question and answer interview. Despite this, I feel that some respondents still felt that as this was an interview they should be directed by what I wanted to know, by my questions, and I think in some cases this went some way to explaining the differing lengths in responses. The focused interview was therefore a very useful tool in enabling me to gather more data from more reticent respondents. Another explanation, which is perhaps pertinent to the issue of 'sensitive' topics, is that some respondents clearly found it more difficult to talk about certain issues related to their illness than others. This may partly be attributable to an issue raised by Brannen:

> Even if a problem is familiar or within respondents' own experiences, they may lack
> a ready vocabulary to express themselves on the subject. (1988,553)

This is a point raised by Walter (1995) who argues that when the dying or bereaved talk about death being a 'taboo' subject they do not mean that there is no publicly available language to talk about death, but that this language does not make sense of their experience. It may be that because of this respondents found it difficult to express themselves to their own satisfaction. There were,

however, at times areas respondents were not prepared to discuss, for example, Heather had no difficulty in talking about her illness and its effects, but made clear during our interview that any discussion about how she felt was not a topic she was prepared to discuss, stating that she "wasn't one for emotional outbursts, you've just got to get on with it." Only on one occasion did a respondent say that she would prefer not to talk about a particular issue at all, and this was not directly related to the research. Later she did talk in a little more detail, and explained that she had not told me before because she had not regarded it as having any relevance for our discussion. Another example, of this occurring was Liz, during her second interview, she said, "You think to yourself ..... Oh I shouldn't talk about it on this, it's got nothing to with this". It would seem that at times respondents have a clear idea about what an interview is, and what they should talk about, and feel that deviating from this is anyway is not appropriate or acceptable. This kind of expectation may be difficult to overcome, but for the purposes of this research, which did not have a prescriptive format it was important to reassure and encourage respondents to talk about issues they felt were important.

Before each interview I explained to respondents that everything they told me was confidential and when I presented their accounts they would be anonymous. Implicitly the research relationship which developed from these initial assurances required both respondents and myself to trust each other.

> ....research methods which establish a high level of trust...... can lead some
> respondents to make disclosures which may not be directly related to the research
> and which are distressing to speak of or to hear. (Cotterill & Letherby:1994:124)

I will now consider the problems which arose for both respondents and myself when information was disclosed, whether deliberately or inadvertently, which had the potential to be extremely damaging. Not only did people initially not want to talk about certain issues because they felt they were irrelevant to the research, but at times people freely told me details about their lives which were only very loosely related to the topic under discussion. On two occasions I know I was told information which had the potential to put both respondents and myself in difficult situations. On

the first occasion the respondent said something which she later regretted. Subsequently I had to

spend a long time reassuring the woman concerned that the interview was confidential, I would

not repeat to anyone what she had said, neither would these particular words be used in any

subsequent written form. Despite these assurances what she divulged obviously concerned her,

and later when I saw her on other occasions, she often joked about how sometimes she said too

much. The danger is that even when informed consent is given by respondents, they may still

reveal information which they would rather have kept hidden.

> .... the person from whom a depth interview is sought.... must agree to give a
> considerable amount of time and effort to the interview. They may be asked to reveal
> a great deal about themselves, perhaps at some emotional cost. Moreover, there is no
> guarantee, that informants will realize before an interview begins what they might
> reveal, in what ways, or at what risk. (Lee,1993,103)

It is impossible at the beginning of an interview to predict all the situations which could possible

arise, which may lead respondents to reveal information they would rather have kept hidden. The

only way available to me to 'protect' these respondents is, as Becker (1967), advocates to avoid

publicising any information which may prove damaging to them personally. On the second

occasion the woman concerned appeared unconcerned, either during or after the interview, about

what she had told me. This information, however, had potential significant consequences for both

her and others, as well as legal implications. I felt that because of the possible implications the

only way to deal with this knowledge was to speak to someone involved in her care. I felt uneasy

discussing something told to me in confidence in an interview, however, different ethical

considerations over that of maintaining confidentiality had to be taken into account. I feel that the

relationship of trust which developed between myself and the HCT and DCC was a crucial factor

in helping me both make the decision to talk to someone else in the first instance, and to remain

comfortable with that decision in the long term.

Other situations which arose during interviews were more easy to envisage in advance, but

equally as difficult to plan for in practice. For example, some respondents did become upset

during interviews, the first time this happened was in my first interview, given this fact, I was obviously quite nervous:

> .....I felt that all my worst fears concerning interviewing sick people were being realised, that I was only serving to upset her further, that she was ill and tired....I felt totally helpless and unable to break through her barrier of unhappiness and pain, and my efforts to do so seemed utterly inadequate. (Cannon,1989,68)

The way I dealt with this situation was never repeated again, and still leaves me cringing when I think about it. I immediately switched off the tape recorder and tried to comfort the woman I was speaking to, which did little to alleviate her distress, and I think went some way to making both her and myself feel more uncomfortable and embarrassed. I learned from this. On subsequent occasions when people became upset I tended to ask if they would prefer to have a break. No-one asked me to turn off the tape record, individuals tended to take a few minutes to compose themselves, and then many managed to continue talking about the topic, which although distressing, they still felt was significant and important enough to talk about in the interview. Despite the fact that these respondents freely gave me their time and co-operation, and were prepared to invest their own emotions in the interviews, there were times when Finch's words seemed all too familiar:

> I have also emerged from interviews with the feeling that interviewees need to know how to protect themselves from people like me. They have often revealed very private parts of their lives in return for what must be, in the last resort, very flimsy guarantees of confidentiality (1984,80)

In conclusion, dividing the discussion relating to methods and methodology between two chapters has enabled me to discuss the practical, methodological and ethical issues and dilemmas in a clearer and more structured way. The last chapter documented the actual research process, as well as providing a description of the study group. This chapter's central purpose has been to address the different ethical and methodological dilemmas which arose during the course of the research. To divide the ethics and methodology seemed unhelpful, because the issues and dilemmas attributable to each were often bound up with those of the other. The aim of this research was to make the experiences, views and words of respondents central to both the research process and its

subsequent written format. In achieving this end I have not adopted one particular theoretical approach when conducting this research, rather the methods and methodology used in this research have drawn on a number of different theoretical perspectives. I hope to have brought out the practical and theoretical issues involved in adopting this approach, as well as to consider in detail the rationale behind using the methods employed and reflecting on the shortcomings and failures of these approaches. I also believe that is necessary for me to consider my own role within the research process: Firstly, because who I am has methodological implications, that is, the data presented herein is a product of my interaction with others. Secondly, I feel that ethically it would be inappropriate to ignore my role and influence. Thirdly, this research has involved a great deal of personal emotional work on my own part, and as has already been noted there is little written work reflecting on the experience of conducting research within a palliative care setting. I feel it is important for researchers in this area to begin to discuss and reflect on this issue.

Chapter 4

Experiences of Care (1):

Patient-professional relationships and communication

In this chapter and the next I focus on respondents' perceptions and interpretations of the health care they received, from when they first suspected that something may be 'wrong'. Respondents in my study reported significant variations in both their experiences of care and their relationships with health professionals. Some spoke positively about their care, others felt at best ambivalent, and in some cases individuals were angry at the care they had received. Despite the fact individuals gave accounts of their own personal experiences it is important to note that common themes and issues did nevertheless emerge. This chapter concentrates primarily on the interaction between respondents and the medical profession (both GPs and hospital doctors) and the nature of the relationship between the two. In it I consider how individuals were told their diagnosis and prognosis, and the relevance of 'open awareness' (Glaser & Strauss,1965) to their experiences. The participation of respondents in interactions with health professionals is also discussed, specifically I explore the relevance of the lay knowledge and experiences which individuals brought to their medical encounters. Finally I consider the explanations that individuals gave for the cause of their illness, specifically their apparent desire to absolve themselves of any responsibility for 'causing' it.

The initial encounter - Consulting the GP

As has already been noted the medical profession continues to be generally respected in contemporary Britain, occupying a position of considerable status and authority.

> The principal assumption [made about the nature of medicine and medical practice] and the one that gives rise to the host of meanings they [the public] associate with doctors and health services, is that medicine is a *science*. If medicine is scientific, to them this means: (i) medical practitioners are superior to ordinary people because they know more, are more intelligent and more advanced in learning than ordinary people; (ii) it requires dedication and self-sacrifice to become a doctor, and it is right to respect doctors for this; (iii) the object of medical science - the health problems

which doctors treat - is extra-ordinary in the sense of being beyond the power of ordinary people to treat and requiring specialized knowledge; and (iv) the implications of the previous points are that medicine and the medical profession are not to be taken lightly. (Cornwell,1984,182 - original emphasis)

A GP is often the first medical person individuals contact when they suspect they may be unwell. However, prior to this individuals are likely to talk to friends and family before deciding if it is appropriate to consult a doctor. If their complaint is deemed to be trivial by others they will not 'bother' a doctor (Stimson & Webb,1975). Freidson (1970) refers to this process as the 'lay referral system'. Individuals consult significant others in order to receive the necessary social sanction before seeking medical advice. The 'lay referral system' is important because without this social sanction an individual is less likely to consult a doctor. This means that at times individuals who are in fact in need of medical treatment may not actually receive it, because they lack the support of those around them.

In my own research it became clear that respondents often talked to their partners, family or close friends before making an appointment to see a doctor. It was also apparent that respondents did not automatically seek medical advice. Gylleskold (1982) notes that the women in her study did not immediately consult their doctor when they first discovered a lump in their breast, some waited a few months, this was also the case for a few women in my study. However, more commonly, individuals tended to delay consulting their GP perhaps rationalising their symptoms as being a consequence of what was going on in their lives. Anna, for example, originally explained her symptoms as being merely tiredness, which she put down to caring for her family. She said:

> I felt like I'd had a bug or something, in fact I was beginning to think that I was a bit of a hypochondriac, because I was feeling very tired and not well, but couldn't really put my finger on it.

Such lay-interpretations of their symptoms are important because:

> People live their problems and illnesses socially, they cannot be viewed as isolated individuals responding automatically to the instructions of their doctor.
> (Stimson & Webb,1975,87)

Not only do such understandings locate the illness within the individual's own life experiences, but they are also important when consulting the doctor. Stimson and Webb (1975) suggest that individuals often tell their doctor what they think may have caused a particular problem. They cite the example of a woman who is suffering from anxiety which she tells her doctor she believes is connected to the behaviour of her "delinquent daughter". They argue that if the doctor dismisses such explanations the relationship between doctor and patient may be damaged; it is therefore important not to disregard 'common-sense' interpretations because they are likely to hold significant meaning for individuals themselves.

Historically, some writers have presented the doctor-patient relationship in terms of the broadly passive patient who both accepts the advice given by doctors and follows it unquestioningly (e.g. Parsons,1991). However, Lupton (1997) argues that today medical practitioners are aware that patients do not automatically trust them by virtue of their position, but that such relationships must be nurtured and developed through a joint process of communication and negotiation. General practice, in particular, has focused upon 'patient-centredness', indeed it appears that a proxy measure for 'quality of care' is actually the quality of the doctor-patient interaction (May & Mead,1998). Despite this new emphasis on negotiation and co-operation it seemed from respondents' accounts that they had a more traditional notion of patient-doctor interaction. Their view appeared to be that of a patient consulting their GP when they believed something was 'wrong', and the doctor, in turn, subsequently diagnosing and treating their condition correctly. However, the experiences of respondents were often far from this 'ideal'. Initial diagnoses were proved to be incorrect. Although, in the first instance, individuals did tend to believe their doctor's opinion subsequently they challenged and questioned these views, when they continued to feel there was 'something wrong'; passive patients they were not. Before considering the difficulties some individuals had in getting the treatment they felt was necessary, it is important to state that some respondents felt they had, and continued to receive good care from their GPs. Katie, in particular, who, although often scathing of hospital based care, frequently referred to

how much she appreciated the care and attention she received from her GP. However, others spoke about the problems they had encountered. As already noted, doctors are generally trusted and respected because of their knowledge and training (Turner,1995). There is, therefore, an expectation that the diagnosis or explanation given by a doctor will be correct, so when individuals were told that the symptoms they presented were "nothing to worry about", they left the consultation often feeling reassured - at least temporarily. Rebecca said:

> I found a lump and went to the doctor's. He said, "It's mastitis we'll keep an eye on it, come back again in three months, and if you're worried in between come back again." Well, you don't worry when somebody says, it's OK it's mastitis, it's mastitis, so away I went.

Ruth had a similar experience. She consulted her GP about a breast problem she was aware of, but left reassured by the diagnosis she had been given.

> She said, "Well it's not cancer, it's something called breast pain," and she gave me an information leaflet about. it She said, "If it gets bad take paracetamol, it's just something women have and have to put up with, and we don't know much about it." So, then a few months later it was getting a bit worse and I thought am I supposed to put up with this forever, is it supposed to get better on its own or what? But I hadn't taken any paracetamol, so I wasn't really worried about it because I thought it must get quite bad for people to want to take paracetamol with it.

Ruth was later diagnosed with advanced breast cancer.

It is important, however, to not over-simplify the dynamics of the GP consultation, because, as Stimson and Webb note, patients are not without their influence:

> People do not hand over all control and decision making to the doctor merely by becoming patients. The aim of the strategies used by both patient and doctor is to attempt to control and direct the consultation along their own desired lines, to persuade the other to recognise or accept a particular perspective on, and orientation to, the problem that has been brought. (1975,71)

This process of negotiation can mean that both parties end the consultation by agreeing on an explanation which is plausible to both (Stimson & Webb,1975; Davis,1988). Problems arise when individuals do not believe their doctor's diagnosis or explanation, still maintaining that there is something which has been overlooked. When this occurs it may lead to the patient's trust in the doctor breaking down; equally, repeated referrals may lead to an individual being labelled as 'neurotic' or a 'time waster'. However, it should be noted, that it is sometimes difficult for an

individual to question the opinion of their doctor because they may feel 'unqualified' to challenge

the diagnosis they have been given, therefore it is often with some reluctance an individual returns

to their GP. Karen's experience highlights this point:

> The doctor examined me, this is in the December, and he said that he couldn't find
> anything wrong with me, I was worrying unnecessarily. But still at the back of my
> mind I felt that there wasn't something quite right, but you take your doctor's advice.
> He kept saying there was nothing wrong, he couldn't find anything wrong with the
> breast.

Despite initially trusting her GP's opinion Karen eventually decided that she would return and see

another GP in her practice, because she felt sure there was something wrong with her:

> [I said], "I'm not happy, this is the second opinion I've had, you're the second person
> who's told me that there's nothing wrong with my breast and I know there is."
> "Well," she said, "I just can't find anything to be worried about, but I can see you're
> not happy." "No," I said, "I'm not happy, I'd like to be referred to the hospital.

Later Karen was referred to a hospital and diagnosed with breast cancer, she returned to her GP.

> They took me through to see this lady doctor, but her answer to me was, well I just
> thought it was absolutely ridiculous. She looked at me, she said, "I can see you're
> upset Mrs Small." I said, "Upset? I'm more than upset, you told me there was
> nothing wrong with me and the other doctor that I saw, he told me there was nothing
> wrong with me. And there is, I've got to have surgery." She didn't know what to say
> for a start. "Well," she said, "You've got to see it in my eye Mrs Small, sometimes I
> see twenty ladies a week with breast problems, and if I referred them all to the
> hospital, what would they say?" That was her answer to me.

Karen's cancer eventually spread to her pleural cavity. Despite subsequently changing GP

practices, she continued to resent her original GPs:

> You see, I honestly think if I'd been sent straight away, but you can't go back to that
> day, it probably wouldn't have gone as far as it has, but you just can't go back can
> you? You know, that's it and you've just got to hopefully hope.

Stimson and Webb (1975) argue that individuals consulting their GP have certain expectations of

the encounter. They expect the GP to undertake certain 'appropriate' actions these include:

conducting a thorough examination, providing a diagnosis and then prescribing specific treatment,

referring the individual elsewhere or providing useful advice. Following on from these initial

expectations Cornwell (1984) argues that patients criticise doctors for three things: failing to

diagnose, or making the wrong diagnosis, not making clinical examinations or doing tests and

finally at the end of a consultation merely giving the patient a prescription - often prescribing the same medicine for different conditions. In the case of my research it is the former two points that individuals were most critical of. Often patients presented themselves to the doctors, having talked extensively with others, only to have their own experience denied or negated. Sometimes their doctor could not find anything, and therefore there was nothing 'wrong', or on other occasions individuals were given a diagnosis which turned out subsequently to be incorrect. Cornwell points out "that the medical profession makes an important contribution to commonsense ideas about health and illness, although not always in ways that are intended." (1984,206). In the case of my own study respondents also made inferences from their doctor's behaviour and treatment towards them. This often affected the doctor's personal image -and the profession more generally - detrimentally, and subsequently damaged the relationship of trust between themselves and their GP. Failure to diagnose - often closely linked to the fact that respondents felt that they should have been referred to the hospital for tests and a given more thorough examination - was the most common complaint voiced by respondents. Despite this, it is interesting to note that although initially expressing feeling angry at the perceived 'failure' of their doctor to interpret their symptoms correctly, with hindsight respondents did make sympathetic remarks about the problems faced by doctors. Ruth said:

> I was a bit cross with the doctor for a while for not picking it up sooner, but that only lasted a while. I thought well it didn't manifest as a lump that you expect to find, and she [the doctor] was only doing what she thought was best. That passed after a while, it took a month or so, because you always try to blame it on someone don't you?

So, although initially resentful of her GP's failure to diagnose her cancer, after a time, these feeling faded and Ruth actually became more sympathetic towards the GP.

Learning diagnosis and prognosis - Encounters with hospital staff

My discussion thus far has concentrated upon respondents' accounts of their interactions with their GPs. However, significantly more time was spent reflecting upon the way in which hospital staff, specifically, hospital doctors communicated important information. In the past it was general practice for doctors to avoid telling patients they were dying (Glaser & Strauss,1965).

Today literature suggests there is a general consensus amongst health professionals that information about the patient's diagnosis and prognosis should be disclosed to the individual concerned (e.g. Veatch & Tai,1980; Seale,1991b; May,1993; Timmermans,1994). In Glaser and Strauss' (1965) terms a policy of 'open awareness' is favoured. Field (1989) suggests that this change in practice is partly attributable to advances in medical technology, particularly in the alleviation of pain, which, Sykes *et al* (1992) claim, can now be controlled in 95% of cases.

> It is recognised that the control and relief of such symptoms as pain and breathlessness contribute significantly to the alleviation and reduction of anxiety, depression and psychological distress among those who are dying. (Field,1989,140).

Indeed health professionals themselves working with the dying comment on the importance of pain relief in maintaining patient hope.

> [Nurse] "I think that one of the first things that we have to get over to them is that we can make sure that they're pain free, because that's one of the things that they get worried about." (May,1995,557)

> [Nurses and doctors] Keeping up hope and reassuring patients about symptom relief were common themes in the replies. (Seale,1991b,945)

It may be that increased disclosure about an initial diagnosis of cancer and later a terminal prognosis is attributable to the fact that doctors may feel they have something to offer these patients, because:

> ...cancer has become more treatable. The diagnosis is no longer a death sentence to be summarily executed. There is now some hope some prospect of a better outcome to talk about and a longer period of remission. (Young & Cullen,1996,109)

However, it should be noted that despite advancements in pain control a recent national survey showed that people were still in pain in the last year of their life (Addington-Hall & McCarthy,1995). In addition although there is a trend towards 'open awareness' it would still be naive to presume that all patients diagnosed with a life-threatening condition always receive open and accurate information. For example, the elderly and those from lower social classes have been reported to be less likely to know about their condition (Gilhooly *et* al,1988). Williams argues that

> ....in Britain, preferences about being told a diagnosis depend on what is believed to be the prognosis, and on the preferences about being told this prognosis. (1989,202)

If individuals believe that the treatments available offer them a good chance of recovery, or at least quality of life, then they are more likely to want to be told. Again this may need qualifying because as McIntosh (1977) notes not everyone with cancer wants to be told their diagnosis. He asserts that some individuals in his research delayed consulting their GP because - even though they suspected they had cancer - few were willing to admit this, and many did not want their GP to confirm their suspicions. Equally once individuals were told their diagnosis they wanted to know differing amounts of information, some wanted to know everything the doctor knew, others were happy to accept the minimum amount.

All my respondents spoke openly about their diagnosis, and many often spoke of their awareness of the fact they were dying. It is possible to argue that this awareness is influenced by two related facts: all respondents were diagnosed with cancer, and all the study group were relatively young - factors which increase the likelihood of individuals being aware of their condition. Despite these similarities in awareness, it should be noted that the way individuals were treated, the manner in which they were told their diagnosis and their relationship with those in charge of their care was far from consistent. I began each interview by asking respondents to tell me what had happened to them since they first suspected something was wrong. Often their stories involved recounting how they were originally told and what they felt like. Liz said

> A doctor came to me in the recovery room and just said, "You have a tumour." I said to him, you know, "Is it canc....?" Well I didn't say cancer, I asked him what it was. He said, "Yes, I'm afraid you've got cancer," and he went away. And then a nurse came in, she was a staff nurse I think, and she said, "Oh they can do so many different things now-a-days for that sort of thing, go home and forget about it." Could you forget it? You couldn't forget it. She meant well.

Katie also felt that the way people are given information is at times inadequate

> [The surgeon] was doing his rounds. And everybody had got visitors, I was in Bay 4 and he drew the curtains around and he was talking and he said, "Well lassie we couldn't remove all of the cancer, there's just a wee bit left." And I thought, hang on, what's this word cancer? And, erm, I remember talking about the most stupidest things, we ended talking about gin and have I tried ginger beer with it? I know it's crazy isn't it? Later all of a sudden there was a tapping on the shoulder and I thought it was Steve [her husband] come for visiting, this was about 7 and it was [the oncologist], and my husband turned up and the same time and [the oncologist] told him to go and wait in the waiting room. He drew the curtains round, now the other three patients in the bay had got all their visitors, so they could hear everything that

he was saying because the curtains aren't sound-proof. And, he was telling me about the cancer, and I said, "Oh yes but [the surgeon] said there's only a tiny bit left." He'd got no right to say this and that, and it's a serious condition and the treatments horrific and there's no guarantees, and all of it, and he drew this picture and left it with me and said, "You start on chemotherapy on Friday the 13th August." And off he went.

Both Liz and Katie subsequently commented on the inadequacy of the way they were told of their diagnosis.

I think the way people are told they've got cancer makes a big difference. I think if the person that tells you is gentle and comforting, it makes a big difference. The doctor who told me was cold, very clinical. (Liz)

I just wish the doctors could find a better way of telling you you've got cancer, than just pulling a curtain around a bed, because it's not sound-proof. And having patients to ring up their husbands or partners or whatever and tell them, it's hard enough taking it in really what you've got, without having to go and tell them. (Katie)

Respondents criticisms of the way they were told their diagnosis are not uncommon, recent research has shown that two out of every five lay-carers surveyed were critical of the way they and the patient received information from medical staff (Addington-Hall *et al*,1991).

Despite the fact it is more common for younger people who are dying to be aware of this fact, it remains the case that doctors may find it difficult to actually tell individuals this.

The surgeons regarded the disclosure of the diagnosis as a routine part of the job, but they also considered it one of the worst. (Taylor,1988,114)

Field (1989) also notes in his study that nurses have greater difficulty coping with a young dying person compared to someone who is older. Perhaps part of the perceived difficulty doctors have communicating with some individuals may be attributed to their age. Sarah, who at 27 was the youngest respondent in the study, said that she personally had never really thought about her own age as being important, until a doctor commented on it. She said

I didn't put an age on it, but then my surgeon, who actually did the operation was saying to me, "Oh, because you're so young they'll do this for you, and they'll do that for you." And, he made me feel a little bit, like, special, because I was young, younger sorry, than a lot people, the way he was saying it

While all the respondents were relatively young, they were not all as young as Sarah, but it would seem doctors at times still had difficulties talking openly about their prognosis. Roger's story illustrates this:

> The guy who I saw, even before he told me that the situation was terminal I could see it in his eyes. I felt, without getting mystic or whatever, that he was trying to tell me something without actually using words. I felt he was saying, "Read between the lines Roger of what I'm telling you." I'm still not sure whether doctors on purpose do not give you the full story, or the full option, again other people I've talked to have had a similar experience:
>
> "OK Doc what have I got?"
>
> "Well, it might be this, it might be that, on the other hand it could be this, or it could be the other."
>
> "Yeah, but I'm asking you what I've got, and what we're going to do about it."
>
> "Well you know you could do this and you could do that, and you could do the other."

Later he rationalised this behaviour by saying:

> He'd been evasive. I think he was hoping that I would understand the situation rather than him having to tell me. I can understand that, I mean he'd got no idea how I would take it, what sort of person I was or anything else, I could've exploded, or whatever people do. In the event I took it quite calmly, but he wasn't to know that.

Individuals often realise that they have a serious illness even when they have not, or are not being, told this explicitly (Glaser & Strauss,1965; Lugton,1987). However, evasion, or difficulty in telling a diagnosis or prognosis, by a doctor, compounded some respondents' anxieties. Understanding their illness and knowing all the facts was very important to some respondents, because for them knowing the truth was easier. Gail said:

> But my specialist Dr M, he's been absolutely marvellous, any questions I've ever asked he's answered, he's always been truthful with me and told me straight what I've wanted to hear. And that I like because I think you've got a right to know, and for me I would rather have known what my chances were all the way through, because you prepare you know, I mean it's always been on the cards that it would come back, it's just the last time, or the second time when they actually got it all I really thought, maybe you know this is OK, but unfortunately..... But there again, he said to me at the time, there are no guarantees it can come back, it's that type of tumour.

Being told the facts was welcomed by Gail and others, but doctors could be too blunt. Fallowfield *et al* (1990), in their study of women with breast cancer, found that the actual treatment itself was not the major issue in determining the individual's state of mind, rather what was crucial was the way in which medical staff divulged information and communicated with the patient. This point is illustrated by Katie's experience. She already knew that she was terminally ill when she went to see another doctor about the possibility of taking part in a new drugs trial, which she hoped would

perhaps lengthen the amount of time she had left, or at least improve the quality of her life. Despite knowing she was dying, she was upset by her meeting:

> "Well, there's good news and bad news," he said, "putting it bluntly, you're dying but you're not dying quick enough to go on it. The CA125[1] is going up but not going up enough." So, that's how you get told.

I have already noted that 'open awareness' appears to be perceived as important in facilitating good communication between patients and staff. However, it is important to recognise that although health professionals may view 'open awareness' as a benefit, this may not be the case for patients themselves. For example, problems may arise when doctors give information to patients who do not want to know their prognosis. As Rachel said:

> [The doctor] said, "I don't know how long it's going to take", so I said, "I don't want to know how long it's going to take thank you very much."......I don't want to think that I'm dying, and yet this woman [the doctor] was sitting in front of me more or less telling me that, as far as I was concerned.

The fact that some patients do not want to know their prognosis makes communication difficult for everyone involved with that individual's care. It may be the case that doctors have the ability to label individuals as sick or healthy, but problems occur when individuals do not want to know, or will not accept the label assigned.

> One kind of doctor tells little because he or she thinks that is what the patients wants (or at any rate should want) and the patients asks little because he or she thinks that is what the doctor wants. (Young & Cullen, 1996,113)

Given the difficulty associated with telling someone they are dying, it is easy to see how the above situation may arise. The doctor tries to 'protect' the patient, and the patient interprets this as a doctor's embarrassment or reluctance to talk, resulting in neither party communicating effectively with the other.

When discussing 'open awareness' it should also be noted that to claim that all dying patients, even dying cancer patients, have 'open awareness' is problematic.

> ....it remained the case that in 1987 a substantial proportion of people knew less than did the professional who cared for them. Just over a third of the patients whose

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[1] CA125 is a tumour marker used to monitor the progression of the cancer.

deaths were expected by hospital doctors and nurses were said not to have known they were dying. (Seale,1991b,947-8)

This situation may be less common with dying cancer patients, who are more likely to be told their diagnosis and prognosis for a number of reasons discussed earlier. However, again it should not be assumed that a situation of 'open awareness' is guaranteed. As already discussed in Chapter 1, Timmermans (1994) divides 'open awareness' into three sub-categories: suspended open awareness, uncertain open awareness, and active open awareness. The difference between these sub-categories is primarily related to how patients understand the information given to them, and how they respond to it emotionally. It is therefore too simplistic to say that today all hospitals pursue a policy of open awareness with dying patients, for this will obviously vary between different conditions, and different doctors. Even when patients are given accurate information they may choose to ignore it, or only to select and retain the 'good' parts of what was said. However, when considering open awareness Timmermans does not address the issue of language; although people may be told their diagnosis, they may not necessarily fully understand the language being used.

> .....communication influences the quality of the experience of dying, and effective communication among caregivers, patients and relatives is essential if the experience is to be a positive one. Both verbal and non-verbal communications are important in interactions with patients, and with dying patients in particular the non verbal channel may be crucial. (Field, 1989,129)

Often the biggest obstacle in achieving open awareness is the way information is given to patients.

While it is true that the first language of all the respondents in this study was English, and this was the language used by medical professionals, it is the case that at times the words and phrases used by doctors to explain things did not always make sense. For example, Pat said,

> One of the consultant's, underlings isn't the right word, but one of his team sort of unannounced, I didn't know she was coming in to see me, I was in a little side room on my own, and luckily my husband was with me, but it was only pure chance. And she just happened to come in, "We've got the results blah blah, it's myeloma, we can tackle this with chemotherapy." She didn't actually say that it was a cancer, but I mean as soon as she said the word chemotherapy I thought, oh my goodness what have I got?

Gail also had difficulties working out what exactly her consultant was telling her:

> I, recognised the cycoma, so I knew it was cancer, otherwise I would really have been none the wiser, at the time I thought what do you mean? So, he didn't really explain it very well.

In both these cases the women were left to make inferences about their diagnosis from the bits of the information which they actually understood. However, it is not only problems of communicating a diagnosis which can leave patients uncertain and worried, explaining the reasons behind certain medical procedures is also important. This can be seen in Rachel's case, she originally had difficulties convincing her GP that there was something wrong with her, consequently she was feeling rather anxious when she was referred to the hospital, particularly when no-one seemed willing to tell her what they were looking for:

> I said, "You're testing for cancer aren't you?"
> "Well, we are going to look for some rogue cells." So I said, "And does that mean cancer?" He came back and said, "We've found some rogue cells." I said, "Are you saying it's cancer, are you?" And they wouldn't actually say to me it is.

Another differential in the patient-professional relationship is that doctors are also often in an advantaged position because they understand the human body in a way the lay person may not. As Roger said:

> Most people have got no idea what goes on behind there you know. Still the same applies to me pretty much, but I've got a rough idea what order things are in roughly and where they lie now.

Young and Cullen (1996) suggest that individuals may become confused by where exactly the organ they have cancer in is, and what it does, rather than by the cancer alone. This kind of knowledge, while obviously important in maintaining and reinforcing power differentials between doctor and patient, may further compound difficulties in understanding medical language. What is apparent from the above is that communicating effectively means more than merely giving a diagnosis. Sykes *et al* (1992) note that the carers in their study wanted to know about symptoms, treatment and prognoses. They appreciated it when this information was given spontaneously by the doctor; when this did not occur they resented the doctor, perceiving that information was being withheld deliberately from them. Added to this diagnoses should be given in a way in which patients can understand, free from unexplained and confusing medical terminology.

'Hope work' and the dying cancer patient

While it is now generally agreed that it is preferable to tell patients the truth about their condition, it is also important to maintain hope.

> The duty of doctors is to keep hope alive, and thence to keep intact the presumption that death can be held off for at least a bit longer. (Young & Cullen,1996,99)

Perakyla argues that health professionals may engage in 'hope work'.

> Staff member and patients are often engaged in intensive interactional work, which may result in a shared interpretation of the manageability of the patient's condition and the possibility of it being medically controlled. (1990,408-9)

Perakyla divides this concept of 'hope work' into two categories: curative hope work and palliative hope work. Curative hope work involves both patient and staff believing that recovery will occur; palliative hope work, alternatively, shifts the emphasis from curing to palliation, viewing the patient as someone who will 'feel better'. Hope work, either curative or palliative, serves to maintain the status of medicine by emphasising its ability to cure or its ability to alleviate pain. However, hope work, does present problems, as patients and doctors sometimes have different frames of reference; they interpret the same words and phrase in different ways.

> They [staff] may consider themselves as talking merely about 'facts', when actually their speech acts are doing the work of reinforcing curative hope. If this is left unrecognised the curative hope work may continue even when the staff's own professional ethos would not accept it. In turn, this may lead to confusion among patients and their relatives. (Perakyla,1991,431)

For example, when Sarah first became involved with the hospice, she felt she was receiving conflicting messages from the hospital and hospice.

> [The home care sister] came the other day and mother was here, and mother mentioned something about death, and that's when she said that [the doctor] would be able to tell you that on my next visit. And I thought to myself, oh my God, because actually no-one's ever said anything about it all before, no doctors or anything.

> [The hospital consultant] just keeps saying to me that there has been a slight improvement in it, all the time. Because I said to this other nurse, "Is everything going the way it should be going?", you know, and she said, "Well yes". Because I said to Mark [partner] last night, I said, "Well how come [the home care sister] is saying all of a sudden this about the children and that about the children?" And I brought that up with a youngish doctor, "Is everything going like it should be?" and she said, "Yes." And they don't weigh up, do you know what I mean?

Encouraging Sarah to believe she need not worry, because everything was being managed in a satisfactory medical way may be an example of this particular doctor using 'hope work'. However, it is also possible that Sarah and her doctor may be interpreting the same terms in different ways, thus leading to a break down in understanding between them. For example, Sarah appears to interpret "Is everything going as it should be?" as "Am I getting better?" To the doctor, however, it is likely that question of this nature will be answered in a way which means that, "The cancer is being kept under control at the moment", or "We have slowed down its progression," not that, "We are curing you."

Perakyla also refers to staff 'dismantling hope'. This is necessary when it becomes apparent that cure is no longer possible and the focus must now be on keeping the individual's symptoms under control.

> .....the point of dismantling hope is that it helps the participants [patients, relatives and staff] to collectively orient to the death of the patient before it actually happens. In this way, work for dismantling hope presents the patient's death as a social fact before the patients dies in the biological sense. (1990,428)

Perakyla's research was undertaken in a Finnish hospital. He claims that there dismantling hope tends to occurs more frequently between staff and the patient's family, rather than with patients themselves. In a hospice, where dying and death are commonplace, it would seem that palliative hope work, and the dismantling of hope occur simultaneously with individuals themselves. Terminal care involves balancing 'realistic' hope with an understanding of the 'inevitable' (Lugton,1987). There is a need to reassure patients that symptoms can be controlled, but also a need to ensure that there is some understanding of the fact that cure is no longer possible. Some respondents were reassured when hospice staff told them their symptoms could be kept under control, and that their deaths would not be traumatic. For example Sarah said

> She [the hospice consultant] said that when I do actually die I won't just die like that I'll start deteriorating and going slowly, know what I mean?

Katie similarly felt happier with the reassurances she had been given by her home care nurse.

> I'm not frightened of dying. I was very concerned about the way I was going to die, not actually dying, but [the home care sister] and [my GP] have said that they'll be there for me and they'll do the best they can to keep me at home. They're not saying

that they will, but they'll do their best, and I know they'll do their best for me so that I won't be in any pain. So, you can't ask anymore from a human being than that, so that's good.

Perakyla (1990) notes that patients may contribute to, and collude with, the hope work undertaken by staff. However, I would suggest that this is not always a negotiated process, but individuals actually internalise this at times. As with information given by hospital staff, consultations between patients and hospice doctors also may not always be interpreted in the way the doctor may have expected. For example, Sarah asked to speak to her hospice consultant about her prognosis, prior to this she remained optimistic about the future. She said:

> If she says three years, for instance, it won't definitely be three years if could be longer couldn't it? You know because they can't get the exact time can they?

After the event Sarah said:

> I forget actually what she said, but anyway, she comes round to it and said, "I think you've actually only got a few months to two years." And we all just sat there, nobody spoke, nobody said anything.

Later in the same interview it became apparent that Sarah was concentrating on the 'two years', particularly when something which she regarded as being positive occurred at the end of the consultation:

> After she told me that I'd only got two years to live she felt my liver and it had gone soft, because last time she felt it you could see it sticking out of my body, do you know what I mean? So, we left the room on a good note because my liver had gone down, it had gone all soft, because that's how your liver's meant to be.

Such optimism should not I believe be merely understood in terms of patients colluding with staff 'hope work', rather it is also relevant when one considers how an individual maintains and constructs their own identity.[2] It may be the case that some observers would categorise Sarah's behaviour in terms of 'denial', however, it may be more appropriate to consider it with reference to 'middle-knowledge' (Weisman,1972). As noted in Chapter 1, this is the seemingly paradoxical state of being aware that one is terminally ill and will die, while simultaneously appearing to deny death.

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[2] See Chapters 6 & 7 for further discussion of respondents' negotiation and management of self-identity.

> ...in spite of accepting that they are soon to die, most of these patients still hope that maybe things will turn out differently. It is quite possible to live with both these possibilities at the same time - imminent death and remission. (Abiven,1996,30)

Respondents often spoke of their awareness of their dying status, but also continued to talk of their plans for the future, or their hopes that an effective treatment would be developed in time to help them. 'Middle knowledge' allows an individual to still function 'normally'. To completely deny or destroy all hope or optimism means that the individual is merely 'marking time' until the inevitable occurs. Hope work therefore also facilitates the maintenance of 'normal' social relationships with others, and allows the individual themselves to maintain a 'living' active identity.

Hospice care and communication

Cornwell (1984) notes that generally her respondents respected doctors, although a hierarchy did appear to exist. She asserts that people tended to be most complimentary about hospital doctors and hospital medicine; were likely to be less complimentary about GPs, even criticising them at times; and finally were sceptical and scathing about the effectiveness and use of maternity and community health services. Seale and Kelly (1997a) also note in their study, although hospital doctors generally gave patients their diagnosis and prognosis with the support of nurses and GPs, it was communication with hospice staff which was judged by surviving spouses to be the best. In my study also it seems that another level can be added to Cornwell's hierarchy, because, in general, hospice staff were much less likely to be criticised than other health professionals. However, before discussing the positive things respondents said about hospice care it should be noted that it would be misleading to suggest everyone was happy with the hospice's involvement, and the way it communicated information; some respondents were unhappy with this, other were just ambivalent. For Sarah and Ruth the problem was not with the hospice *per se* but the number of different people they had involved with their care. This is obviously relevant when one considers that part of the hospice philosophy is to provide 'holistic care' for patients, which at

times may mean the involvement of more than one individual, as well as people from other

organisations. Ruth said:

> There were just lots of people coming round and introducing themselves, being
> sympathetic and saying, "We're here for this and we're here for that." I think at first
> it was bit like over-kill, because I had a Macmillan nurse, and charities lady and [a
> home care sister] from LOROS and the doctor came round. I wasn't sure what
> everyone was for.

Sarah had two young children, she wanted to arrange who would look after them after her death,

she hoped that she would be able to do this without too much outside intervention, something she

dreaded. She said:

> You meet so many different people and you have so many different names to
> remember, it just sends your mind blank. We've got enough bleeding people
> involved with doctors and things, you don't want social services on your back,
> because once they start they don't stop. They'll be camping out on the bleeding front
> lawn!

As already discussed, a central tenet of the hospice philosophy is open awareness. Some

respondents, however, expressed feeling angry when hospice staff made reference to their dying

and death; clearly highlighting the problems which can be encountered in pursuing an 'open

awareness' policy:

> Gill: And one thing she did hurt me in saying and I didn't like
> it.........She [hospice consultant] asked me, if it did come to it and it was a real
> problem at the end, if I wanted to be at home or in hospital, which wasn't very nice,
> because two days after a woman died in the bed across the ward from me, you know,
> and she was younger than me and, you know, it sort of hits you, and I wondered if
> there is anything, you know.
>
> Catherine: And no-one else had mentioned that, talked about dying apart from
> the hospice doctor?
>
> Gill: No, and she just well Frank [husband] wasn't there at the time.....
> that's the only thing I thought ooh golly, I wonder how long I have got

Gill went on in a subsequent interview to say that she was really unsure about why the hospice

had been contacted. Similarly Ruth appeared to feel rather ambivalent about hospice involvement,

she said:

> I'm not really sure what they're [the hospice] there for. I mean she comes round and
> sees how I am and everything and that's nice, but apart from that we just get to know
> her in case we need her. I'm not really sure what she's there for.

Some of the uncertainty about the need for hospice services seems to be closely related to the hospice image of a place of death. As Rachel said:

> Well, I must admit I was frightened and I was very, very depressed when the nurse said to me "Have you thought of LOROS?" I said, "Well that's where you go to die." And I honestly felt that once I'd gone up there that would be it.

While the image of the hospice did not worry some respondents, indeed, they were often happy to move away from hospital based care, for others it was more difficult to deal with. For them it represented "the beginning of the end" as Margaret put it. However, Pat and Ann took a slightly different approach, they had no objection, indeed enjoyed, attending the DCC regularly, however, when I mentioned 'the hospice' to Pat she told me that she had never been to the building, and that she generally felt rather uncomfortable about it, referring to it as a 'taboo'. Sarah had a different image of the hospice, she did not criticise it, but said that she felt it was 'middle class'. She said:

> I don't find them [hospice staff and volunteers] over bearing or anything like that. I think they all seem to have come out of the same mould, do you know what I mean? They all seem to be the same kind of person.....I find them all very nice people. At first I thought they were a bit too nice, you know, but I don't know. They're all so what's the word? Very middle-class, everybody, they talk a lot about Marks and Spencer.

Although some respondents did point out negative aspects of hospice care, the concerns voiced were generally much less critical than those made of hospitals. Generally it seemed that respondents welcomed hospice involvement in their care. In particular, many respondents welcomed the way hospice staff communicated with them. Margaret said:

> They were so good, they told us more in one interview, then the other doctors had told us all along, and I feel they're the experts and I can tell them anything.......How it was likely to continue, and they didn't gloss over, they said, you will gradually get weaker, it's to be expected, but when you know what's coming I don't think you worry as much.

Or in Heather's words:

> It was suggested that I went to LOROS, and they've been absolutely brilliant, everything, every tablet, every move they're going to do they tell me and ask you if it's alright it's so different

Similarly Katie said:

It [the hospice] was more relaxed, it wasn't like a hospital, no it was nice. I just sat there and this lady came up and said, "Sorry to keep you waiting." No-one wearing a uniform, it was very much laid back and friendly, homely, yeah you wouldn't realise you were in a hospital until you saw when I went down to see the doctor you saw the bays with the beds in and that was it. You were shown into a room and the doctor came in. They were all very friendly, they were super.

It is interesting to note that these positive remarks about the hospice often related to the amount of

time individuals felt they were given, and their own active role within the consultations.

Limited time

Time is an important factor when considering the nature of patient-doctor interactions and is

something I turn to address now.

So the trend towards more openness has not yet embraced the whole of the medical profession by any means. It has been uneven. The wrong people are still sometimes told the bad news; they can be more precise about the time left to a patient than they should be. A lot of the things that go wrong are the result of doctors *not having enough time* to talk to patients. (Young & Cullen, 1996,114 - my emphasis)

However, it is often the case that the time of each individual in the interaction is differentially

valued:

Time is another factor which act as a constraint on the interaction [between doctor and patient].....The doctor's time is seen as a valuable commodity by him, his ancillary staff, and by patients, and his time is generally seen as more valuable than that of his patient.....the patient may be accused of wasting the doctor's time but the doctor will rarely be accused of wasting the patient's time. (Stimson & Webb,1975,59)

When individuals feel their doctors spend 'enough' time with them they are more likely to speak

positively about their consultations. Cornwell (1984) notes, in her study, a doctor's personality

and manner were generally viewed as being less important than their ability to do their job and

treat people effectively. This was particularly the case among older people who tended to be less

critical of a doctor's apparent shortness on the grounds that they were 'busy'. However, younger

people tended to be less willing to accept such behaviour.

Despite these complaints about doctors' manner, the main expectation that people in the study had of doctors was that they should do their job and *be seen by their patients to be doing their job*. (Cornwell,1984,185-186 - my emphasis)

As I have discussed earlier patients expect to be diagnosed correctly and given the appropriate treatment. However, 'doing their job' is more than diagnosing and prescribing. Doctors need to be able to communicate effectively with their patients. As already noted all my respondents were under 67, the majority in their 40s and 50s. In the light of Cornwell's comments it is not surprising that at times respondents expressed feeling unhappy with the way their doctors treated them. Some of this discontentment can be related to the amount of time doctors have available to spend with each patient. Pat said:

> But I must admit, it was only when [the doctor] came to see me, *he gave me as much time as I wanted* to ask questions, but sometimes the more you ask, I was getting in a bit too deep, he was starting to go a little bit too technical and he lost me, while he kept it on the basis of the flower garden and the weed I could grasp all of that. (My emphasis)

Pat recognised and appreciated the fact that her doctor gave up his time, despite the fact that the explanation he had given her had become too technical for her to actually understand. In Sarah's case the consultant actually used words she understood, however, it is evident that she may not have had enough time to actually digest and fully comprehend the significance of what had been said to her:

> [The doctor said,] "It looks very suspicious to me, that it may be cancerous." It didn't really dawn on me what he was saying to me until I actually walked out of the office, because he was saying to me, "You'll have to come in and have it taken out and have further tests done on it to see if it is or it isn't, we can't actually tell until the lump's actually out of your body. And then coming out of the room, and I think I just walked through the hospital in a daze, I thought to myself, has he just told me I've got cancer in a nice way, or what? I didn't really know, you know, but as I was getting home, going further home, it was dawning on me that he'd just told me that I'd got it. Do you know what I mean?

Time is also significant if one considers that a great deal of it is spent waiting for appointments, waiting for test results and sitting in waiting rooms. Making patients wait at hospitals for appointments implies that their time is of little value. By contrast, they are expected to be grateful and accommodating when doctors eventually get round to seeing them after hours of waiting, because it is implied that doctors' time is precious (Young & Cullen,1996). Time spent waiting for test results was particularly difficult for respondents. Gail and Liz said:

> The worst part is when you've got your suspicion and you're waiting for hospital appointments, you're waiting to go for a test. You know in your heart what the answer's going to be, but then you've got to wait for your results, and it's all about waiting. That eats away at you, if you could get it done there and then it would be so much better, it's the waiting. (Gail)

> It's the waiting in between not knowing which is the worst thing, not knowing and waiting for the tests to come through, and wondering you know if there's something wrong, you don't know what it is but you fear the worst. And I feel now I know the worst, I won't say I'm happy with it, I mean you can't be happy with news like this. But at least I'm not in between I'm not worrying what next. I'm not sort of in a limbo wondering all the time. (Liz)

Restrictions on time may also account for other common complaints. In particular respondents often said they felt their concerns were ignored or dismissed by doctors. Clearly this may be a result of doctors not having 'enough' time to spent with each patient. The difficulty of communicating with staff is highlighted by Katie's account below:

> I wish they would listen. And I've found this, apart from my GP, you go to hospital they don't listen. They'll talk and you give your reply and it goes in one ear and out the other, and they don't seem to understand. Why aren't they a bit more plain spoken? Why don't they call a spade a spade, than go round the houses all the time? So they'll say, "OK Mrs Clark these are the facts, these are the side effects, obviously you'll need time to think about them, think about them and come back, if you want any help just ask." But it's, "Yes what can I do for you? Well, what do you want to know? Well why do you want to know that?" You know I'm the person that's affected that's why I want to know. It's that that makes me cross. I think they're not making it easy for you, or you're not even being treated like a human being, you know, where you're listened to.... Everything's black and white and they just don't listen to you, the trouble is they just don't have enough time, I don't know whether it's bad organisation or lack of money or whatever, but no matter which hospital you go in they're under pressure. It's like it all the time, it really brasses me off, because you go in there, you have to wait 2 to 3 hours, which you accept, you don't mind, well it's inconvenience more than anything else.

However, another problem which may arise in patient-professional interaction is that it is sometimes the case that individuals do not raise their concerns with doctors. This may occur again because of limited time, because patients are less likely to ask questions of health care staff who are perceived to be 'busy' (McIntosh,1977).

> ...for their NHS patients as much as for any other, the key to good communication is not so much talking as listening, and always asking the patients if they have any *further* questions to ask. But they may have no time to listen. There are just too many patients. (Young & Cullen,1996,125 - original emphasis)

Poor patient-staff communication has profound consequences for patients. When individuals feel

they are not being listened to they begin to feel more anxious. Such feelings are compounded if

they are made to feel that they are little more than an irritation and an unnecessary drain on the

doctor's time. This would seem to be the case below. Rebecca was referred again to the hospital,

despite initial reassurances that there was 'nothing to worry about', she remained concerned about

a lump in her breast:

> The specialist was very, very shirty with me and he just said, "I've told you what my opinion is, would you like another opinion?" I said, "No, not really, you know, it was just that I was worried about it." "Well if it'll give you peace of mind we'll do a biopsy, if you want your body to be scarred it's your decision." I said, "Well, I think for my own peace of mind, I don't mind a scar, I'd rather have the scar and know than carry on like this worrying, because I am worrying about it." He took me down to theatre. Two days later I got the phone call, come in, it's malignant and it's in the glands.

Later she said:

> I really do feel that at the beginning I was more annoyed at the treatment, not for me, but for people in general, that people should have to go through that, that you should have to insist before you should get anyone to listen to you. There must be so many cases, well there are, everybody you speak to they say, "They said it wasn't." There must be more they can do on the screening side. So as I say that just made me really cross....sometimes I think if I'd just sat back I wouldn't be here now if I'd listened to everything that everyone told me, I'd be in a hole 6 feet under wouldn't I? It's your life in your own hands you've got to be in charge.

Time is of the essence if patients and doctors are to communicate successfully. Individuals need

time to digest the information they are given and to ask questions.

> It was clear the opportunity to ask questions and the repetition of information, often at a later date, were particularly important to carers. (Sykes et al,1992,234)

While it is clear that respondents also wanted 'enough' time to discuss their concerns with

doctors, when this did not occur, some tried to rationalise their doctor's behaviour.

> A good doctor is one who 'does not hurry you', who 'takes time to listen', and yet allowances and excuses are made for a doctor who might otherwise have been criticised on the basis that the pressure of work does not allow him enough time to devote to his patients. (Stimson & Webb,1975,60)

As already noted Ruth in retrospect was able to sympathise with her GP's failure to diagnose her

breast cancer; similarly Roger said he could understand how difficult it must be for a doctor to tell

patients they are terminally ill. On a slightly different note both Katie and Roger justified the problems they encountered at the hospital with reference to recent NHS changes. Katie said:

> I felt sorry for [the doctor] and his team because they're jam packed when you go down there, sometimes you have to wait for three or four hours because they're so busy. When we've gone to see him, when we've walked in he's getting the results up and reading them up and looking at the scan when we walk in, because he's not had time because of his work load. And only two machines for radiotherapy. It makes me so cross what they waste money on, well I call it waste, because OK art is nice, but what about the practical things, what about curing people? What about helping the consultants to make their lives easier?

Roger commented on what he'd observed during a short hospital admission:

> The problem was as simple as they were one and a half nurses short and it made a dramatic change in the level of care. Well there was no care basically. They did what they had to do, or what they could do and that basically was it. I'm not saying they're not capable of it, they're only allowed to do what they're allowed to do, cash and everything permitting, but you could tell that most of the time.

"Can you help me?": Encounters with other personnel

During the course of their care individuals often spent a significant amount of time on the telephone to their local GP practice as well as to the hospital, speaking to receptionists and administration staff, who effectively act as gatekeepers to medical professionals. Patients may be worried or distressed when they telephone, and these members of staff have the capacity to alleviate or further compound these feelings. The influence of these staff can be seen by considering Rebecca's and Katie's experiences. Rebecca's problem arose when she moved to live with her daughter. Her GP had promised to send her notes from her previous hospital to one in Leicester. She later found out he had overlooked this, but in order to discover this she had to telephone the local practice:

> I was starting to become more and more disabled and I was hobbling round like a little old woman. I kept ringing the surgery and saying, "If you could tell me which doctor it is I would ring the hospital myself and ask the secretary if she's any idea how long it will be, because I really am getting quite uncomfy now." "We can't tell you that." Again, I thought, do I pick them out, is it me? There's got to be one though in every surgery one little jumped up so-and-so. And really and truly it doesn't cost anything to be nice to people. She said, "Maybe you should go privately, you'd get seen quicker then wouldn't you?" At which stage I just collapsed in tears.

It was a member of hospital administration staff who upset Katie. At this stage she had decided not to have any further curative treatment for her cancer, but was hoping to take part in a new drugs trial which might retard the cancer's progression.

> It was the same when I was due for a scan I rang up because I hadn't had my appointment through. I said, "I'm really sorry to pressure you but I've got an appointment in 2 weeks if I don't have it done pretty soon they won't have my results when I come for my appointment." "Well, is it urgent?" I said, "Well [my GP] wants me to have it done." "Are you having treatment?" I said, "No, I'm not having any treatment, I've decided not to and I've got terminal cancer, I don't know if you call that urgent or not." "Well, if there's nothing else that can be done for you," she said, "it's not urgent, we've got people who want to go on treatment." And she put the phone down on me.

The attitude of this particular woman raises an important point. It would seem that staff members (both medical and lay) may make assumptions and interpretations about individuals who choose to either not have any treatment, or to cease existing treatments. The notion being, presumably, that the patient has a moral responsibility to try any option which may either cure them or at the very least prolong their lives for a few more weeks or months.[3]

Patients' roles and understandings

It is difficult to give a 'typical' description of the patient-doctor relationship, because clearly interactions vary from one individual to another. For example, some cancer patients will want their doctors to take full control; they want to believe in their skills and ability to 'cure'.

> Whatever the professionals do or do not do, it is unlikely to be challenged by patients who are ill and therefore preoccupied and usually lacking in confidence. (Young & Cullen,1996,113)

However, it is too simplistic to see all patients in this way. Even when initially respondents felt that their own knowledge was inferior compared to that of the doctors, they often subsequently gathered information in order to improve their understanding. Roger said:

> I did what I think most people do when they find that they've got something like this, you get as many books together as you can to find out what the hell it is.

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[3] See later discussion of Parsons' (1991) 'sick role' for further consideration of this point.

Similarly, Sarah initially said she felt uncomfortable questioning medical decisions, however, as time progressed this changed as her own knowledge of her illness increased, through talking to other patients and reading books:

> Sometimes you don't really like to ask because you don't really know. But now I've been going, I don't know how long is it, nearly a year now I've been ill and I feel like if I want something I can ask for it, if there's a question I want to ask I can ask it now. It's like I asked her how will I know if the cancer's coming back, growing again, and she said, "You'll know," and I said "Well how?" "Your body'll tell you, because when you've got ill before that was your body telling you that your cancer was there, or there was something wrong in your body." But then when I think back about it I wasn't ill at all, I was just tired, but I put that down to just having a baby, so I can't see myself getting ill if I didn't get ill before the operation or even after the operation then I can't see me getting ill again. That's why I want the blood test as well, because I know I didn't get ill. Some people get ill with their cancers don't they and I didn't really click on until she said that to me, then I went home and thought about it. I thought I wasn't ill before I was just tired.

Related to this latter point, and the 'lay referral system' discussed earlier, it is possible to argue that the patient-doctor consultation does not necessarily involve the 'powerful' doctor and 'compliant' patient, but rather it may be more appropriate to see it as a 'meeting between experts' (Tuckett *et al,* 1985).

> We conceive of the consultation as a meeting between one person who has, by his training and experience, access to scarce and specialist knowledge and another person who has, by experience, immersion in culture and past discussion a set of ideas about what is happening to him. (Tuckett *et al,* 1985,217)

Not only do individuals gather their own ancillary information from a wide variety of sources, they are also 'experts' to the extent that they 'live' their illness; they experience it and understand it at first hand. These explanations are important because they enable individuals to understand their illness in the context of their own lives. Such explanations concentrate upon the multi-dimensional nature of their identity and not just on the one-dimensional identity of patient.

Richman (1987) points out that patients with serious illnesses often try to build their own explanatory models in order to understand their diagnosis within the context of their own biography. As in other research, respondents in my study often tried to provide accounts for why they had developed cancer (e.g. Cornwell,1984; Cannon,1988). This often involved using medical

explanations but also incorporating this with commonsense understandings. Cornwell refers to this a 'public account'.

> The background assumption about the nature of health in public theories has *both* scientific and commonsense legitimation. The assumption is that inequalities in basic health are 'natural'; some people have better health than others because they are born with a 'better' or a 'stronger' constitution. The concept of the individual constitution is perfectly compatible with the medical theory of genetic susceptibility but it also fits with the commonsense theory that inequality is a natural phenomenon - whether it is inequality of intelligence and ability or inequality of health - which informed the attitude people in the study have towards employment and which they use to legitimate hierarchies of all kinds. (1984,150 - original emphasis)

Alternatively, Cornwell suggest that 'private accounts', are often discussed with reference to three factors: paid employment, position in the sexual division of labour and finally past experiences of dealing with providers of health and welfare provision.

> Almost invariably the private accounts of illness show that one or more of these three factors affect the way in which the person giving the account had felt or dealt with their illness. (Cornwell,1984,134)

Private accounts seek to locate individuals' experiences within the context of their own lives. Such explanations are rarely given as fact, but merely suggested or implied in individuals' stories. Public theories on the other hand sought to identify who or what was to blame for the cause of an illness, which even if not directly stated was often clearly implied.

Like Cornwell, I found that when respondents spoke about how they believed their cancer had started they attributed it to several widely held popular beliefs including: stress, pollution and family history. It is interesting to note that such explanations often involved explaining clearly that the illness was not in any way the individual's own 'fault'. It is possible, to this extent, to see a parallel here between the views of respondents and part of Parsons' (1991) 'sick role'. Briefly, Parsons outlines four characteristics of the 'sick role'. Firstly, the sick role allows individuals to be exempt from their normal social responsibilities, although this requires legitimating by a doctor. Secondly, the illness is not the individual's responsibility. Thirdly, being ill is not desirable, and the individual wants to, and is obliged to recover. Finally the individual must "seek technically competent help" (Parsons,1991,427), generally from a doctor, and co-operate with the

doctor in trying to recover. Parsons saw this role as being functional to society; necessary for maintaining both its cohesion and the smooth running. Turner (1995) outlines four general criticisms of Parson's 'sick role': firstly, it fails to take into account the lay consultation which occurs prior to visiting the doctor. Turner argues that there is a need to make a distinction between a patient role and a sick role because, as already noted, without peer sanction some individuals with genuine illnesses will not consult a doctor. Secondly the 'sick role' assumes that individuals should have enough understanding of their own health to realise that something is wrong and thus to consult a doctor, but once in the consultation with the doctor this lay-knowledge should be ignored and the patient should accept the doctor's advice unquestioningly. Thirdly Parsons' notion is based on the assumption that all individuals are treated equally by the doctor regardless of age, class, ethnicity and gender. Finally, the sick role is based on the experience of acute illness; the doctor and the patient both have a mutual - and more significantly an attainable - goal to restore the patient to full health. For many people Parsons' conceptualisation of the 'sick role' may indeed have familiar elements. However, such a model is, "full of optimism and recovery" (Richman,1987,88), often far removed generally from the experiences of individuals with long term chronic and degenerative illnesses.

Despite these criticisms Parsons' model is useful at this point in my discussion. In Parsons' 'sick role' individuals must be seen to not be responsible for their illness. Similarly, it would appear that respondents also perceived that they should show that they were not to blame for the genesis of their cancer. Such beliefs may be reflective of a broader expectation within society that individuals have a moral responsibility to, as far as possible within the context of their own circumstances, maintain their own health. When individuals fall ill, therefore, it appears they feel they must try to explain why, and further, if they have in anyway contributed to its causation they should seek to justify their own 'harmful' or 'socially unacceptable' behaviour. This can probably be best understood by considering wider societal attitudes towards certain conditions. Illnesses are seen as being more 'acceptable' when the individual is not seen to be at fault. For example, there

is a clear difference in general public attitudes towards individuals with breast cancer (an apparently blameless disease) compared with attitudes towards people with HIV/AIDS (a condition popularly associated with certain 'deviant' groups - with connotations of it being a justified retribution for their 'unacceptable' behaviour). Within this broader context it is easy to see why individuals with cancer often try to absolve themselves of any responsibility (Tishelman,1997). Respondents themselves engaged in this process. However, not only did their explanations often remove any blame from themselves, but they were also part of searching for meaning and understanding of their illness within the context of their own lives (Fife,1994; Dirksen,1995). For example, Edna blamed her ex-partner:

That's what made me ill, the stress of living with him made me ill.

Liz also felt her cancer was stress-related:

It all ran into one, this business with this cancer. My mother had a stroke, she couldn't move, then she died. Then my son's wife left him with two boys, and then I had this problem. So really, I've had a very stressful few years, so whether that's got anything to do with the cause of cancer I don't know... You've not got to blame anybody, there's nobody to blame really. But you'd like to work out why, why did it happen, what did I do wrong, or something like that. I just put it down to stress and leave it at that.

Gill blamed the "sprays on the fields and things like that". Both Gaynor and Anna spoke of the history of cancer in their family, which they believed had in some way limited the shock they felt when they were actually diagnosed. Anna said:

My mother had died of cancer and her mother had died of cancer, and I always in the background thought, oh it'll get me one day. My mum was only 50, and I always had this feeling that I would, you know, get cancer before 50, or at 50, or something. I never sort of felt why me, or that, probably because I always expected it I think.

Cornwell observes that:

The most common explanation of cancer in public theories, however, involved a *combination* of an internal predisposition towards the disease and some kind of external 'trigger' or shock which precipitates onset of the disease. Many people expressed the view (attributed to medicine) that everyone has cancer and cancer patients are simply the unlucky ones in which the disease is activated. (Cornwell,1984,158-9 - original emphasis)

Roz's explanation of her cancer relates to this point, she said:

I don't know what started that first cancer off it could have been anything, because you've got cancer there in your body, I've always known that, but it just needs something to trigger it off apparently that's what happened to me.

Smoking was also mentioned as a possible causal factor, however, in both instances there was a desire to move any blame away from the individual. In the first instance it was a consultant who reassured Roger he was not to blame:

> He [the consultant] actually made the point of saying, "Are you, or have you been a smoker?" And I said, "Yes." "Well, take it out of your mind that smoking had anything to do with the cancer that you've got, it had absolutely nothing to do with it." I mean he didn't go on to recommend smoking! But, he was quite definitely making the point that I wasn't to blame for this cancer I'd got, I'm sure that if I'd got lung cancer it would be a different story.

Roz was worried that her smoking could be the cause of her cancer, and sought reassurance from her husband that this was not the case:

> I said to my husband "Do you think the cancer I've got is caused by the cigarettes?" and he says, he did when he first heard I'd got cancer, but when he knew that the cancer was on my ovaries he thought different about it. He says when he knew that my liver and kidneys and my lungs were alright he felt different then. He didn't think for one minute that it could be the cigarettes that give me cancer. I thought I must have done something. I must have, I fell down the stairs, sometimes I think, I wonder if that's what triggered the cancer off, I don't know.

Both these examples show how medical understanding of illness influence commonsense ones, but more significantly show how important it is that individuals feel absolved of responsibility for their illness.

Respondents also explained and understood their illness in the context of their own biography. They 'consulted' with other lay people some of whom had similar diagnoses and they read books to help them understand more. Such knowledge and behaviour is perhaps indicative of the lay 'expert' as suggested by Tuckett et al (1985). Individuals, therefore, wanted more than a diagnosis from their doctors, they wanted to be able to also make sense of their illness within the context of their own lives; using their own 'life themes' (Zlatin,1995).

> Life themes are beliefs we develop about ourselves over the course of our lives as we participate in our environment and create our social reality and sense of self. (Zlatin,1995,196)

With these 'life themes' in mind, good communication with medical staff was dependent upon more that mere diagnosing and prescribing. Individuals' own experiences and understanding of

their illness had significance and meaning within the context of their own lives, and respondents felt happier with their doctors when they felt they listened to their concerns and beliefs.

From this discussion it is apparent while it was important for individuals to maintain and trust in medical procedures and treatments at the same time individuals sometimes made decisions about their treatment which was far from what might be expected of patients. Being a dying patient was obviously an important aspect of respondents lives, however, being a patient and dying were only partial reflections of the whole person. Prior to their involvement in medical care individuals had been involved with many more valued roles, identities which maintained their social status rather than detracted from it. While it was sometimes difficult to break away from a one-dimensional image of a patient, particularly during prolonged treatment, it is important to recognise that outside the GP consultation room, out-patients or hospital ward individuals continued to fulfil their previous roles. Being a patient, who is also dying, is only a partial image, there is a need to also reflect upon the other important aspects of individuals' lives which they themselves value, and it is respondents' multiple-identities I consider in more detail in Chapter 6 and 7. However, in the next chapter related to individuals' experiences of care I discuss other moral responsibilities which individuals may feel obliged to conform with. For example, in terms of the treatment they are 'expected' to agree to, I explore the ways in which individuals justify their decisions not to try or continue certain therapies. This discussion leads me to consider whether there is a 'dying role' which contains within it certain moral responsibilities and expectations.

Chapter 5

Experiences of Care (2):

Treatment and the 'good enough' death

In this second chapter related to respondents' experiences of care I consider the different treatments they underwent during the course of their illness. Respondents tended to divide their discussions about the care they received into three sections; they made a distinction between 'surgery', 'treatment' (radiotherapy and/or chemotherapy) and 'morphine'. Throughout the following discussion I use the terms and distinctions used by respondents themselves. I begin by examining briefly individual's thoughts and feelings about the surgery they initially underwent; I then consider their experiences of radiotherapy and chemotherapy. Morphine was the most common drug used to control individuals' pain, and while in general people were happy with its effects, some were ambivalent about actually taking it. Moving on from this point I consider more broadly the notion of control during the treatment process. I look at how individuals negotiated or asserted their control at this time, and I explore what behaviour other people appear to consider to be 'appropriate'. In the latter part of the chapter I consider what individuals said about their own dying and death. I examine how their hopes and fears were informed both by deaths they had witnessed, or heard of prior to their diagnosis, and deaths which had occurred whilst they were in a hospital or hospice. At this point I suggest that to speak of a Good Death in a prescriptive way may not be particularly useful for individuals themselves and a more reflexive and fluid concept of the 'good enough' death may be more useful.

As Perakyla (1989) notes, individuals do not just have bodily experiences but what is also important is their subjective experience and their social relationships. Although in this chapter I specifically address different parts of individuals' treatments, it is important to note that common inter-related themes are apparent throughout. Hope is an important issue throughout individuals'

care, and in this chapter I consider how individuals maintained and readjusted their hopes as time and treatments progress. Much of this section also relates to issues of control, specifically the tensions which arose at times when individuals and those in charge of their care had different expectations. Control and hope are both important factors in negotiating and managing an individual's own personal identity. This chapter shows how respondents adjusted and reaffirmed their own identity during the course of their illness, and the complexity of this process. The issue of identity is considered in more detail in Chapter 7.

Surgery

As discussed in the previous chapter, after initially consulting their GP individuals were usually referred to a local hospital. Hospital medical staff usually diagnosed or confirmed a diagnosis; further, it was at the hospital that different treatment options designed to 'cure' or alleviate pain were managed. The hospital environment (at least initially) offered an array of different treatment options, and in doing so gave individuals hope.

> A hospital visit could also bring hope of betterment. The main treatments - surgery, radiotherapy and chemotherapy - were given there and, while they were all liable to be unpleasant, particularly in their side effects, they were also often followed by a remission which allowed people to resume some of their old activities. (Young & Cullen,1996,440)

Although surgery clearly offers an individual hope of a 'cure', it is important to note it may also, simultaneously, remind them of less optimistic outcomes.

> .... the operation meant not only a possibility of cure but also a confrontation with their own death. (Gyllenskold,1982,315)

All the respondents in my study had undergone some surgery during the course of their illness. This often occurred shortly after their diagnosis when individuals were hopeful of recovery. Even when operations occurred further along the illness trajectory (for example in the case of bone marrow transplants) surgery continued to represent a new juncture of hope, where remission could be round the corner. Although the actual effects of surgery could present their own problems, physically removing a diseased body part, 'cutting' it away, gave individuals hope of a 'cure'.

The importance of this can be seen in the following account. Gail had lyposarcoma, she hoped that an operation to remove different parts would be successful. She said:

> They removed my left kidney, my spleen, part of my pancreas and they actually got all of the tumour. And we thought this is great, you know, perhaps this time this is it.

Similarly, although Karen felt some sense of loss for the breast she had removed, the fact that her surgeon had been able to physically cut away the cancer held significance for her. This notion of 'cutting' the cancer 'out' was very important to her and later, when the cancer spread to her pleural cavity, she still hoped that it could be 'cut out'. Surgery, the physical act of removing the cancer, 'cutting it out', gave her hope.

> In three weeks I'd had two lots of surgery which was horrendous really, you get over one shock of having one lot of surgery and then you've got to have your full breast removed....I coped with it very well actually, because in my eyes, once they'd taken the breast away the cancer had gone and I was relieved. I hoped that it would have been in the other breast rather than where it's gone now, because if I'd had the other breast taken off, because at the minute you feel a freak because you've only got the one breast. I'd've been a lot happier about that. OK, it's not very nice to think that you're going to have another breast off, but I think it would've been a lot easier to cope with in my eyes. I asked [the consultant] if there was any chance of surgery he said no. I was hoping they could cut bits out, which I've heard they can do, because I've seen it on TV.

The fact that for Karen surgery was no longer a viable option illustrates how, although surgery does indeed offer hope, becoming aware that one can no longer have anymore surgery reduces that hope, and may force individuals to confront less optimistic outcomes.

It is interesting to note that the individuals who spoke most about the effects of their surgery were women who had undergone surgery for breast cancer. Others by contrast tended to mention their surgery only briefly, explaining what had actually been removed rather than how they felt about this. Part of this discrepancy may be understood thus:

> The breast represents an integral part of the female body image. This means that when a woman is faced with the loss of a breast she may regard this as a threat to her feminine identity or an injury to her own personality and integrity. (Gyllenskold,1982,238)

> Patients with breast cancer endure many of the most feared aspects of illness. They frequently undergo disfiguring surgery, extended radiation and chemotherapy with toxic side-effects, and are confronted with the very real threat of death. (Spiegel,1990,1422)

Like Cannon (1988) I found the accounts women gave varied: some were happy to have got rid of what they perceived to be a diseased, and potentially contaminating body part, others continued to feel both self-conscious and a deep sense of loss. It is generally understood that the experience of having breast surgery (particularly mastectomy) can have a profound effect on a woman (Lovestone & Fahy,1991). This was certainly the case for Heather who had her surgery a number of years ago, she said:

> Because not feeling like a full woman is horrible, it really was. It was, I think you feel so mutilated....I just prefer to be on my own [in a ward side room] and that's since my mastectomy, you know, because I don't know, it's when I felt partly a woman I just didn't like getting undressed.

Such feelings accord with those of the women involved with Gyllenskold's (1982) study, who also referred to themselves as 'mutilated' and/or 'half a person'.

The possible psychological effects of losing a breast are not only well documented in academic journals, but also in newspapers and popular 'women's' magazines. Such media articles frequently present 'heroic' (Seale,1995) accounts about cancer and its treatments; how 'readers' came to terms with and successfully lived through their experiences. Such widespread coverage has meant that women (and men) have become more aware of the possible physical and psychological effects of such treatment - an example of how 'professional' views and ideas can inform and shape lay views and understandings (Cornwell,1984). For example, Gill actually changed her mind about having her breast removed after her husband remarked that her decision may have other long-term implications:

> They said I could have the lump or my breast off. At first I thought I'd have the breast off you see, I was all ready, but my husband said, "Well I should think it over." The doctor told him to shut up, because it was my decision. But after I thought about it he was right, because sub-consciously if I'd have had the breast off straight away it could've caused a lot of problems, psychological, in the mind.

It is difficult to know whether it is Gill or her husband who is more concerned about how the loss of her breast may affect the sense of Gill as 'feminine'. What this statement does illustrate, however, is the complex consequences a mastectomy may have on both a woman's own sense of self and also on others' perceptions of her.

Loss of a breast can also detrimentally affect a woman's sexual relationships (Lovestone & Fahy,1991). However, Rebecca commented on the fact that she had not found this to be the case:

> They did a radical mastectomy, they just whipped the lot out. His theory being that if we remove enough then we get everything hopefully. And I had a good run really I suppose, 13 years. I didn't have any chemotherapy or radiotherapy, just that mastectomy and that was it.....Obviously it had an impact on me, on your sex life particularly, I think that was very hard maybe to come to terms with, because your body plays an important part, the female more than the male. I've discovered since anyway that I've had no problems what so ever, I really haven't, it made no difference. It's who you are not what you've got or what you've not got. I think I've been lucky really. I mean a lot must depend on your partner cos I imagine it was hard for them to accept at times, but again there's ways round it, you make yourself attractive in other ways.

Rebecca's account is interesting because, although aware of suggestions that the loss of a breast may cause sexual difficulties, she herself had not found this to be the case. This might, perhaps, be attributable to Rebecca's own multi-faceted identity, where her breast, although important, was not central to her concept of self.

> Although the breasts are important to the patient's identity and self-valuation, they do not constitute an irreplaceable part of her self-esteem. Her self-esteem is based both on her experience of being 'wife-lover-mother' and on her experience of having satisfying work outside the home as well. (Gyllenskold,1982,941)

Clearly mastectomy does have a profound effect on some women, however, it is equally important to note the way in which women come to terms with their loss and continue to live their lives in the way they want.

Chemotherapy and radiotherapy

When surgery had occurred 'treatment' usually followed. Respondents spoke about chemotherapy and radiotherapy, and it is these I refer to when I use the word 'treatment'. Treatment was often given initially in the hope that it might be curative, but in the latter stages of illness it was usually used to alleviate symptoms. However, no-one in the study made a distinction between curative and palliative treatment. Two respondents, Liz and Roger, had neither chemotherapy nor radiotherapy; Roger made the decision not to have treatment. In addition, when I interviewed Ruth she had not yet started her palliative radiotherapy. Of the remainder of the study group who

did have treatment, six had chemotherapy only, three had radiotherapy only and seven had both. Given that some individuals had both radiotherapy and chemotherapy during the course of their illness it is interesting to note that chemotherapy was most frequently discussed. This stands in opposition to Cannon's (1988) research, she found that individuals were more likely to express their fears and worries about the effects of radiation rather than chemotherapy. However, this may be partly explained by the fact that she recruited her respondents through a hospital radiotherapy unit. Gyllenskold (1982) notes that individuals find it easier to talk about their treatment after the event. It may be for this reason that, having had time to reflect on their experiences, with hindsight, individuals were able to more clearly identify the more difficult aspects of their treatment. A further reason why chemotherapy may have been talked about more is that it is systemic, physically invasive and applied intravenously; it affects the whole body. Radiation therapy, alternatively, tends to be applied to a specific part of the body. It may be that the localised application of radiotherapy allows an individual to regard themselves as having a diseased body part, in contrast the systemic nature of chemotherapy may cause an individual to define their whole body as diseased, which in turn is likely to also more profound effects on an individual's sense of self.

Common themes arose when respondents discussed chemotherapy, particularly its toxicity and side-effects. For Roz and Katie the symbolism of the 'black bag' was poignant:

> I was a bag of nerves just seeing this black bag. I just thought it's going through my body, something's going to happen any minute. There were so many reactions they were saying you get with this chemotherapy, I could lose my hair. I was a bag of nerves at the whole thing. (Roz)

> It was quite funny because I had a bag of saline, then you have your bag of chemo and that's a black covered bag, obviously because of the light. But I think, oh why don't you just put a skull and cross bones on it. (Katie)

Some respondents said that merely thinking about the chemotherapy they had still had a profound effect upon them. Rachel said:

> Even going down the hospital I can be sick, even thinking about it [chemotherapy]. I don't know what it did to me, I couldn't even drink, and they kept saying to me, "We'll have to take you back into hospital and put you back on a drip because you're dehydrated." I didn't want that, because even now my hands are so bruised, and my

veins are so, they just collapse when they see a needle coming to them now, they really do feel bruised and I felt I'd really had enough.

Judy was participating in a drugs trial prior to beginning her chemotherapy. The drug she was taking and the chemotherapy caused her to have an extreme reaction which subsequently left her fearful of having the palliative chemotherapy suggested by the hospice doctor. She said:

> My first experience of that first day of chemo was horrific. You get there early in the morning, all these patients, come and go and you're still sitting there. I'd gone on my own and I will never forget that day, I felt as if I was being by-passed, as if no-one was bothered. I was sitting there in that god-forsaken place and that's how I felt.....[After] I was phoning the [hospital] in the middle of the night. I was phoning places like Japan to my sister and saying please you've got to do something to help me....Tuesday of the third week when I had a break down I went totally mad. I was running up and down stairs I was standing on furniture. Half past two in the morning I was hallucinating, got out of bed, screaming at the top of the stairs, ran down stairs smashed through a double-glazed front door. Picked my husband up threw him against the door, smashed two of his ribs, 15 year old daughter upstairs hysterical. 6ft 2 son came downstairs and wanted to punch me. When my husband came round he said, "Don't! But get her down on the floor." So he literally pushed me down on the floor and got on top of me, and then, when I calmed down a bit, I mean I smashed completely a double-glazed front door, glass everywhere, wrenched the handle off, literally just wrenched it off, was going to smash all the pictures in the hall, I was going to smash anything I could lay my hands on.

Judy later used this experience to justify her reluctance to have any further chemotherapy:

> And then she [the hospice doctor] said the dreaded word, "He might decide to give chemotherapy." And I thought, I don't really want it, but she said, "It will be different to last time. Really, it's not preventative." Which I know it's not. "Really, it's to make your quality of life as best as possible, so you can breath better and do things better."

The most difficult aspect of having chemotherapy, according to respondents, was the side effects. Indeed it would seem that these were often more difficult to cope with than either the actual treatment or the physical effects of the cancer itself. Ann said:

> There ain't much to it having this chemotherapy and shit it just makes you feel not so brilliant. I mean the actual treatment is just an injection really going into your vein once you've got used to having it, it's scary at first. There's not much to the disease really except what it could do to you. It's like having a blood test having the treatment.... It's not the disease which kills most people it's the treatment but if you didn't have it then it would be the disease that killed you. What can you do?

As noted in Chapter 1 the body and its physical appearance, are important to an individual's identity (Shilling,1993). Just as the loss of a breast can affect an individual's sense of self, so the loss of hair as a side effect of chemotherapy, also caused considerable distress.

The loss of hair (along with eyebrows and eyelashes) was viewed by many women as an intensely personal affront which literally added insult to injury. Hair was seen as something unique and personal. (Cannon,1988,169)

Ann Dennison, in her autobiographical account of her experience of living with ovarian cancer; wrote:

What upset me most was not the sickness or the stay in hospital but the thought I was going to lose my hair....My hair was important to my identity. I was vain of it; very thick, dark and shiny it had always been seen as one of my assets.....I would look different I would look like a cancer patient. Day in and day out it would remind me. And everyone else. I had only just gone back into the world and other people's reactions had always been closely related to the fact that I 'seemed so like my normal self'. Now I wouldn't be any more. (1996,26)

My respondents said:

Well, I didn't like that [the chemotherapy]. I put up with it, you have to do, but I didn't like that at all it made me feel ill. I lost my hair and I didn't like that at all, but anyway I got over that.... I didn't like the chemotherapy, I used to cry a lot. I wasn't physically ill all the while but I think I got depressed because I didn't like it at all. I didn't like the way I looked, I didn't like the way I felt. My hair, that upset me, but then I got over that as well, like you do. (Gaynor)

They don't understand what you're going through - chemotherapy - because I just think it's been horrendous. I think it's the worst treatment I've ever gone through. I mean I've lost all my hair, that wasn't nice losing all my hair, although it is growing back again, When it all dropped out after two sessions of chemotherapy I just couldn't believe it, some people's hair just goes thin. So that was another battle that you have to get over. (Karen)

Other side-effects included nausea and depression. However, as with the loss of hair, respondents felt they were able to live through these if they continued to believe that the treatment could ultimately be successful.

....am I going to lose my hair, am I going to feel deathly? I was very sick, but in the end they managed to control it with anti-sickness drugs. Having said that ant-sickness drugs stop you physically throwing up, but you just feel nauseous instead. I never know which is worse. But you don't mind feeling rotten on the chemotherapy if you know it's going to be doing it's job. I'm now classed as being in remission but as he [doctor] explained to me it does tend to creep back. (Pat)

I was really down today, but I've been told that the chemotherapy can make you like that anyway, can make you feel a bit depressed. But I had a really bad night last night and that's probably what it was. I couldn't get off to sleep and I dunno your mind starts working over-time you start thinking about things, you know, not nice thoughts some of them are not, and then you try to pick yourself up again. (Karen)

Individuals not only commented on the short-term side-effects they had to cope with, but, like Gyllenskold's (1982) respondents, they worried about the long-term effects of their treatment, and

its ongoing consequences. Edna and Karen both alluded again to the toxicity of the chemotherapy and the effects they felt it had, and would have, on them.

> Even when you're in remission your body's worn out with the treatment you've had. There are days when I feel I'm 97, you feel old before your time, and it's the treatment that's done that not the cancer. I'm 49, but I feel old inside, older than I should feel and I put that down to the treatment because it wears your body out. (Edna)

> I think the chemo, I'm coming to the end of my treatment now and I'm thinking, your body's at rock bottom it must be because the chemotherapy, the drugs they pump into you they're all poison toxins, and I've been told by the nurses, "It's just playing havoc with your body." (Karen)

As noted earlier, the symbolism of chemotherapy, as well as its physical effects, clearly had a profound effect upon individuals. Gail said:

> They're putting the lines into you and you know that this drug that is going through you is so toxic, and you think, "What the hell am I letting them do to me?" And there was one stage when I just felt like ripping it all out, but then once I'd calmed down and I was OK, but the first time, that initial time it is horrific it really it; it's terrifying. It just makes you feel so ill, I mean they give you all the drugs they can but it still makes you feel ill, it makes you feel so weak, because it affects your blood cells doesn't it? Then when it's your last course of chemo you think, oh god I've made it, no more, that's the nicest one of all, and you're counting the bags, how many bags you've got left to go on.

Although chemotherapy was often difficult to endure, like Cannon (1988), I found that respondents had conflicting feelings as their treatment came to an end. In one respect they were relieved that it was over, but at the same time they dreaded being told it had not worked and they would have to have another course; or, more worrying, that everything possible had now been tried, and there were no more options available.

Like surgery, treatment offered hope to individuals, even those who had been told that there was no chance of being cured. Ruth said:

> [After the diagnosis] I'd already written myself off and I was thinking they're going to tell me that I've only got six months to live, so when they actually started about treatment I was quite chuffed in a way. It sounds weird. They confirmed I had cancer, but they said they could treat it, well give me some treatment for it, so I was relatively happy.

Other individuals also felt that the notion of having treatment, which they thought health professionals viewed as being beneficial, was incongruous with the fact their cancer could not be

'cured'. Again such difficulties may be attributable to problems in communication between staff and individuals. Rebecca said:

> The radiotherapy is pain relief, every time I go they say, "You know this is just pain relief?" But I don't know I can't understand that when they say that, because if it kills off the cancer cells it's got to clear a bit up hasn't it? I suppose there's others waiting to jump back in again isn't there?

Although Sarah had actually been told by the hospice consultant that she had "three months to two years," she still saw treatment as being beneficial, given the improvements she had experienced in the past. She said:

> I want to know if it's, you know, growing again, then I'd like something to be done about it, because surely the sooner you start some more treatment on it the better. When I first started my chemotherapy my liver it was that large that I could hardly breath because of it pressing on my rib cage and me breathing and laughing and things like that it hurt all the time.

However, it was not only current treatment which offered individuals hope, future possible medical breakthroughs, although less tangible, also produced some optimism. As Rebecca said:

> Well, there's something coming out all the time, this ewe tree, you just don't know do you. The Tamoxifen[1] itself, I mean that's been fantastic, that was a good break through, and as I say that slows it down. He wouldn't put a sort of time limit on it, he said, "Well we can't say that say we can give you another 16 years," because it was then 16 years since the first time, and he said, "but it would be nice if we could." And I just keep that in my mind.

Such optimism is not necessarily a representation of an individual's denial of their dying status but, rather as discussed in the previous chapter, individuals although aware of their diagnosis may still hope things turn out differently (Abiven,1996).

> Many women appreciated the arbitrary nature of the disease and treatments but countered this with the hope that if they could live long enough then sometime soon a cancer cure would be discovered......Such hopes were bolstered by media reports of advances in the 'fight against cancer' and the tendency of the medical profession to adopt an empirical approach which stressed therapeutic innovation.
> (Cannon,1988,196)

Although individuals did have hopes that medical science may find a 'cure' just in time to benefit them, they realised this was a less realistic than maintaining their faith with existing treatment. Gail said:

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[1] Tamoxifen is the most widely used anti-cancer drug used. It is used particularly in the treatment of breast cancer.

I think the first time you're so full of hope and you've got all these things like chemotherapy and radiotherapy and you think, "I'll crack it, piece of cake. You'll do it, just fight you know." But as it comes the second times, you know, you've had the chemotherapy, it's not worked. You know you've had the radiotherapy, it's not worked. Then I think it gets a bit harder because you think well what have we got left now you know?

Ann said

It's not the disease so much I'm worried about it's more the chemotherapy because I know I've only got one more go. There's only one more cocktail they can give me and it's like the last chance do you know what I mean? And that's what's scary... I'm a bit scared. I was a bit tearful last week, but I'm better now.

As time progressed respondents acknowledged that even maintaining hope in their current treatment became progressively more difficult as different treatments were tried with little or no success.

Morphine

As noted in the last chapter, cancer pain can now be relatively well-controlled. However, it has not been eliminated completely (Young & Cullen,1996). Respondents sometimes found pain difficult to cope with particularly, when it was too extreme, because it affected every aspect of an individual's life. Katie said:

The pain's like a niggling period pain, and when I get like that I must admit I do think I'm really fed up with this. I'd like to just not wake up one morning, but I've only felt like that twice since I've given up working.

Morphine is the strongest analgesic available to cancer patients and all the respondents in this study were taking it in some form, often at the same time as having other treatments. Being prescribed morphine was initially difficult for some because it represented, "the beginning of the end". Gaynor said:

When they said we're going to put you on some morphine I thought, "Oh God I don't want that, I'm on my way out if you give me morphine, oh dear." That's the first thing you think isn't it? - because I've never had it before and I thought, "Oh no." Of course they had to explain all this to me and as soon as I'd got that in my head I'm fine, so I'm quite happy with the situation now.

Respondents had differing understanding of morphine and how it worked. Anna understood that without it she would still be in pain. Alternatively Gill felt that as she was no longer in pain she

should cut down the number of tablets she was taking. As discussed in the previous chapter such differences may be attributable to difficulties in communication with professionals; individuals may have been given information about their pain control but not fully understood what was being said.

> The pain's gone because I've got whatever's in here, this magic potion. I don't understand morphine very well, but I know they're controlled drugs and everything, so obviously I'm on a strong dose of whatever. But I should be grateful for that at least, you know I'm not suffering like I was. (Anna)

> They [MSTs[2]]don't seem to be doing much, they gave 'em me when I was having back pain, but the only time I get that now is if I get in an awkward position or I've sat like this and I go to get up. Also early in the evening I feel tired, so I want to cut it down a bit you know. I don't really feel that I want them now, not so much. I think you shouldn't really take pills unless you're really in pain. (Gill)

As with surgery, radiotherapy and chemotherapy, morphine is not without its side-effects. Most notably individuals spoke of feelings of drowsiness when they initially started taking tablets or increased the amount they took. Katie commented on another side-effect which she found rather difficult:

> I tell you what I do get now it's the side effects because I'm on MSTs now. I get the shakes, the tremors and honestly people think, "Jesus she's been at the drink a bit." It's quite embarrassing you know. Also if I go to sleep whether it's in bed or here [on the sofa] I'll jump, my neck'll jump, or I'll jump, it's not as thought I'm dreaming that I'm going to fall or something it's not like that, it's nothing it just happens. I'm like a jumping jelly bean.

As in Cannon's (1988) study although individuals had little or no influence over surgery, radiotherapy or chemotherapy they were able to maintain some degree of control over their pain control.

> The use of painkillers could be manipulated to cope with specific events, or alternatively not taken in order to avoid side-effects which would interfere with some activity. (Cannon,1988,159)

Some individuals resisted taking 'too many' painkillers if they wanted to avoid feeling tired, for example if they wanted to go somewhere. Respondents structured their own days, and those of their families, around the morphine:

> At home I get up about 7 I do a few jobs and the morphine hasn't kicked in, and I have to go down and lay down for 3/4 of an hour til the morphine kicks in and then

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[2] Morphine Sulphate Tablets (MSTs) are slow release tablets commonly used in the pain control of malignant disease.

I'm fine. And I usually rest between 1 and 3, and that routine usually keeps me good. (Katie)

....morphine tablets make you a bit sleepy, so on top of my 180 having another 40 makes me fall asleep 20 minutes after taking them. So I have to make sure that Alex [son] is in the house because I can't really fall asleep with him playing out with his friends. So I have to make sure he's in the house and the house is all locked up before I can fall asleep, because he can put himself to bed. (Sarah)

The ability to alter or adapt pain relief to suit individual's needs was a source of empowerment for some individuals. Individual management of pain control is a particular policy pursued by many hospices, precisely because it allows individuals to take back some control, and manage their treatment around their lives, rather than living around their illness (although this may still occur to a large extent). Sarah in particular found this to be very different to the more regimented medical encounters she had experienced in the past.

And she [hospice doctor] was saying to me take as much as you need, you balance out your own medication. And I thought, oh that's nice because normally you go there you get a prescription from your doctor and they tell you take three a day. But they were actually saying to me take as much as you need, or as little as you need, play with it, that's what she said play with it, and I thought. Oh that's nice.

As is apparent from my discussion thus far feeling in control was a recurrent concern for respondents. While it was clear that individuals at times willingly agreed to operations and treatment regimes which medical staff felt to be appropriate, they did so in the hope that by co-operating they would become well again. Individuals made informed choices about different issues within the context of their own lives. At times it was appropriate to allow others some control over their lives, at other times it was important to reaffirm their own control. This could be in a seemingly 'insignificant' way by managing their own morphine, or in other more 'significant' ways as will now be considered.

Enough's enough

....the process of treatment and care may be seen as a process which attempts to lead the patient to behave in the ways considered appropriate to the illness which has been diagnosed, a process often called "management" by professionals.
(Freidson,1970,329)

Maintaining 'hope' in the dying cancer patient is an important part of the caring role (Hockley,1993), and as already noted in the last chapter 'hope' is an important factor in the treatment of cancer generally.

> ...staff saw hopeful patients as contributing to their own treatment by remaining optimistic; tolerating the disease-effects of treatment in a more accepting, less complaining manner; making fewer emotional demands on staff and thereby enabling staff to conserve energy that would be needed for "cheering them up"; and finally, as models for other patients and a source of hope for staff. (Buehler,1975,1356)

It is not only expected that individuals will pursue the medically prescribed treatments but also that they will do their best to remain optimistic and maintain a 'fighting spirit'. It could be suggested that when individuals cease to behave in the way deemed to be 'appropriate' by those responsible for the management of their care the situation becomes a little more complicated.

All respondents had some surgery and the majority had either chemotherapy or radiotherapy or both. However, Roger chose not to have any treatment at all, and Katie and Gail chose not to have anymore surgery or treatment. This is contrary to Cannon's observation:

> The cancer patient dare not refuse active treatment (although she/he may refuse painkillers) because to do so would be to appear to choose death. (1988,166)

I would argue that while individuals who chose not to have any/more treatment did so in the knowledge that this meant they would die, they did not choose death. Rather they wanted to live the remaining part of their lives without the restriction of treatment, its inevitable side-effects and flimsy possibilities of prolonging life. Sometimes individuals with a terminal condition choose not to have any/more treatment just to give their bodies a rest (Stimson,1974; Cannon,1988) and also to free themselves from a regimented routine imposed by frequent hospital visits. Buehler (1975) argues that on diagnosis individuals decide whether they are 'living' or 'dying'; the implication being that 'dying' is negative. I would argue that this is too simplistic, in my own research I found that individuals were often both aware of the fact that they were terminally ill, and therefore 'dying', but still defined themselves in terms of 'living'. Being aware that they were 'dying', rather than being 'negative', actually meant that individuals focused more on their 'living'.

Individuals made informed choices from the information they were given and decided whether the benefits were worth the costs. Gail said:

> They explained to me that if I left things as they were I've got weeks to live. If I had this stent done it would give me months, I was so ill, I really was ill all the time throwing up and the prospect of going on for more months I couldn't take, and I declined. No, I'll let things take their natural course, that's what I've chosen.

Katie felt that her decision to cease having treatment was not approved of by her consultant. She said:

> He went on a bit about being only 50. I was too young to go on the scrap heap. I said, just because I'm not going to have treatment doesn't mean I'm going to sit down and die. I'm going to carry on.

It is possible to argue that just as Parsons' acute 'sick-role' contains certain expectations of the individual so, in the case of the chronically or terminally ill, other moral obligations are also apparent. Not only should the individual seek medical attention, but they should also concur with the expectations of medical staff and wider society about how long they should continue pursuing certain treatments, and when such treatments should cease. As I have already noted a patient who develops a 'fighting spirit', who has faith in the treatment and is subsequently 'hopeful' and optimistic about its outcomes is valued by staff. Not only are such patients easier to care for on an individual basis but they help boost staff morale, and act as role models to other patients (Buehler,1975). It would seem that cancer patients are expected to pursue every possible option available to them if this is deemed appropriate by those in charge of their care.

Difficulties arise with the notion of a 'sick role' if one considers that it is often the case that at any one time individuals will have a number of people from different organisations involved in their care. Different professionals are likely to have varying hopes for, and expectations of patients. Consequently they may be subject to a number of different moral obligations and hence have a multiplicity of 'sick roles'. For example, both hospital and hospice staff may encourage the patient to have a 'fighting spirit', but this is likely to mean different things within different organisations. Such variations may cause difficulties and confusion. Further, what is deemed

'appropriate' is also likely to vary from patient to patient. As I highlighted earlier, Katie's doctor was keen for her to continue with treatments because he felt not doing so implied she was "giving up" and he believed at 50 she was "not ready for the scrap heap yet". It may be the case that the potential 'social loss'[3] of an individual's death may affect whether their decisions are seen to be acceptable. Health professionals, and society in general, often find the deaths of younger people more difficult to deal with (Field,1989; Payne et al,1996) because of this there may be a greater tendency to encourage younger people to continue to have treatment which may prolong their life. This in turn may lead to individuals feeling pressured to pursue something they themselves may not want. Seale and Addington-Hall (1995) argue that elderly respondents in their research were more likely to express the view that they should die soon, on the basis that they were 'too old'. They also found that individuals caring for the elderly (excluding spouses) were more likely to express the view that it would have been better for the person to die sooner than they had. Given the implications of this research, it may also be the case that it is easier for health professionals and family and friends to accept the decision of an elderly person to stop having treatment (even when this is against medical advice) than it is to accept the same decision made by a younger person. This is perhaps because in our society death has become firmly associated with the elderly, and when it is someone who is relatively young who is dying it may be more difficult for others to accept (Mulkay,1993).

Individuals weigh up the options before them when considering to cease having treatment. They make a conscious informed decision, it should not be viewed, as professionals may label it, as 'non-compliance' (Forsyth et al, 1984). When Roger, Katie and Gail spoke about deciding not to have any/more treatment they always justified their decision, illustrating that they were being 'rational' in their decision. The most common reason they gave was to have 'quality of life' and to regain control. Such justifications show the rational nature of the decision they made, and emphasise that the decisions were not made quickly, but rather were carefully thought through.

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[3] See Chapter 1 for more detailed discussion of Glaser's (1966) concept of 'social loss'.

'Quality of Life' is a term frequently used within medicine in general, and palliative care and research in particular, and it is interesting to note how it has been adopted by patients themselves as part of their everyday language (cf. Cornwell,1984). However, it is important to note that individuals did not define what they meant by 'quality of life', they seemed to take its definition for granted. It seemed that they used it to mean the life they wanted to live. At times 'quality of life' meant choosing to be physically uncomfortable if this enabled them to participate in something they wanted to do. Their definitions appear to be highly individualistic and fluid, in comparison to more prescriptive usage of the term in medical discussions. However, what remains apparent is that 'quality of life' was very important to all three respondents who spoke about choosing not to have any/more treatment:

> If I took the chemotherapy that would increase my chances by a factor of one, maybe one and a half, the problem being that six months of that time would be spent having chemotherapy. So, it didn't take long for both myself and my wife to, you know, work out the odds and decide not to take the chemotherapy. So, we're going with it as they say. (Roger)

> They said that staying as I am I've got a week, if I had this op it would give me a month, but I'd rather have a few good weeks and perhaps stretch it out rather than be poorlier. (Gail)

Katie wanted to feel in control, she spoke about how the decision she made was not just for herself but also for her family:

> We asked the odds, and he said, "Well obviously while you're on it, for six months you'll be fine and that'll give you three more months". I said, "But hang on, I could have that anyway," and I said," I'm not going to have any quality of life during those six months, that's why I refused chemotherapy in the first place."...The more people I spoke to the more confused I got, so I decided for quality of life than the old type of chemo, when it wasn't even 20% chance of it containing it, it's not a lot for 6 months of being very ill. When you've got this you don't just have to consider yourself you have to consider your children and your husband so that was what I decided......I think it's wonderful that they've got these trials and they're doing things, and the reason why I would like to have gone on, well obviously, it would be wonderful if it could've extended my life, but it was more, I would like to have done it more for Gina [daughter] and her generation. But at the same time not, I suppose I want my cake and to eat it. I would have gone on the [drug trial] tablets where the only known side effects was the swelling of joints, but the Taxel[4], that's a different ball game, because they'd have to put all the tubes in to inject everything and to stay in hospital every Monday night, sod that. Then I'd have one good week out of four for six months, and on top of that you might perhaps get three more months. I mean that's really something to get you jumping about at isn't it? I said, "No." They can't seem to understand this. I said, "Thanks ever so much but I've really had enough of

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[4] Taxel (pacitaxel) is given intravenously, and is used in the treatment of ovarian and breast cancer.

hospitals." I said, "I know there's people that have been in hospital more than I have and I'm very lucky compared to lots of people, but this is how I feel." And they do not listen. I feel as though I've had a good life, which I have, I'm 50 I've got two kids who have turned out to be two nice human beings and I've been happily married for 29 years and there's nothing that I haven't done or I haven't, you know I've done anything that I've wanted to do. So that's how I feel and if I'm going to go I'd rather go in my own way digging the garden in two weeks time, than go in hospital with a tube up trying to adjust things to extend my life, through having that you could have three more months, I could have that anyway, I'd rather go on my own terms, than the cancer telling me when it's going be through. And they can't seem to understand, I don't know if they've got to have everything neat in packages as well, "You're 50, you're not on the scrap heap yet, so we can do some tests on you, come on there's a bit left in you." But the majority of the tests you've got to be worse or older to get on them, now to me, somebody who's not on the scrap heap, this is their terms not mine, I'm 50 you're not on the scrap heap, why don't they give it to people like that then wait until they're really on their last legs before you go on it. Like [the drug trial treatment] I could go on it, but my CA125 was going up each month, but wasn't going up enough to qualify to get on it, so you've got to wait 'til you're worse. If you're worse, how can you fight against the side effects, surely everything would make matters worse, so who the hell makes these rules?

It is clear that Katie felt that the criteria for participating in the drugs trials were incongruous with the pressure she felt was been exerted on her not to 'give up'. The attitude of this doctor, who seemed to imply that by not having any more treatment Katie was 'giving up', clearly shows how individuals can be made to doubt the decisions they have made. Having treatment is not the only way an individual can continue to 'fight' their cancer. For these individuals (and others) continuing to live their lives as normally as possible, away from a hospital environment, allowed them to reaffirm control over their own situations. However, it is interesting to note, that despite the fact that Roger's, Gail's and Katie's decisions were clearly rational to them, and pertinent within the context of their own social environment, they still took the time to justify their behaviour. It would seem that wider - both lay and professional - 'moral expectations' on the terminally ill (particularly those who are relatively young) to have all the treatments available, may have a profound consequences. In order to avoid being labelled as someone who is 'irresponsible' or 'incapable of making decisions' for themselves there is a further moral imperative on individuals to provide plausible and justifiable reasons to explain their decisions to go against what is expected.

The management of dying and death

During the course of their illness, all respondents had spent at least some time as an in-patient in a hospital ward, some had also either stayed in the hospice or had visited others there. During their time spent in different health care settings some were present when fellow patients died. Such experiences lead individuals to comment on the in/adequacies of organisations' management of death as they themselves perceived it. Some individuals had not witnessed deaths in either environment, but had never the less built up an image of what it would be like to die in a institution from their time spent attending clinics or as an in-patient. Sarah said:

> I think at the hospice, I think if I went to the hospice, you'd have more privacy, They'd put you in a side-room wouldn't they? If you were in the hospital, I think you'd just be stuck on a ward and when you die you just die and they bring the curtains round you.

Later:

> I think if I do go up there [to the hospice] I'd prefer to go into a side-room to die, not in a ward. Well, I don't suppose I'd care at the time because I'd be so weak. Because that's what she [the doctor] said to me, I'll just start getting weaker and weaker, and I suppose, well I've been weak already when I just can't move and I suppose when I'm like that I just don't care what happens to me, as long as you're warm and comfortable it'll be alright.

It is interesting to note that Sarah was unaware of hospice policy to allow individuals to die on the ward, rather than removing them to a side-room. It may be that as she associates the hospice with more personal autonomy (for example, as discussed earlier with regard to managing her own morphine) she also assumes the same autonomy will be apparent during her dying, which is clearly not always the case. Honeybun *et al* (1992) conducted research in a UK hospice to examine individual's reactions to the deaths they witnessed. They argue that witnessing another patient's death (specifically a peaceful one) may be reassuring to other individuals in the same room or ward. They conclude by saying:

> ....all things been equal retaining the dying patient in the room with other patients would appear to be in the interests of other patients. (Honeybun *et al*,1992,72)

However, Margaret found the hospice's policy of allowing people to die on the ward rather problematic she said:

> Margaret: They said, oh, she died soon after you settled down last night. But you knew, you get to know, you can tell by the look on 'em that they're not going to

last very long. I mean time before last when I was in there was the bed in the middle, and there were two people died in that bed, one night and one the next and they were in the next bed to me, well it feels a bit near home then, you know, when that happens.

Catherine: You felt a bit uncomfortable about that?

Margaret: I did really, because they don't move them out you know when they know they're dying, they just leave 'em there in that bed, and you wake up in the morning, and, the beds empty and that's it. .....The only thing I have ever said was, "Wouldn't it be nice if you moved them out into another room." The nurse said, "Oh that's not our policy here." So you've just got to get on with it ain't you?

Margaret and Sarah both referred solely to the hospice, however, Ann, contrasted her experiences

of seeing people dying in both a hospital and hospice setting. She visited a friend while she was

dying in the hospice, and felt concerned about the care she saw her receive. She said:

> If I was in hospital, right, and I was dehydrating I would be on a drip, right. Or if I was on a catheter, and my catheter was filled up, it would be emptied. But at the hospice it didn't seem to happen, right, you'd have to be begging someone to change Chris' [friend] catheter, or she needed to be on a drip in everybody's opinion, but it never happened, until a week later when she was all shrivelled up.

Again about the hospice she said:

> But it was horrible, it was just horrible, and urgh, just wasn't nice at all and everybody was sort of elderly and, I'm going to die. I thought, "Oh God, I'd hate to be there like that, lying next to six people that." Maybe I'd be lying like that as well, I don't know, but I just didn't like it.

By contrast, it seemed that for her witnessing others' deaths during her time in hospital was

reassuring:

> I'm not scared of death, I've seen that many people die since I've got ill, that I know it doesn't hurt, you know it's like going to sleep. I'm not frightened of dying.

Despite saying this it became apparent during Ann's interview that the ward she went into at the

hospital tended to move people they knew to be dying out of the main ward. Such a policy is in

direct opposition to hospice policy, but clearly something she felt was a good thing. She said:

> In the ward, I'm not sitting around, usually, I'm not sitting around people I know're gonna die today or the next day either.... In the hospital, once they get really poorly they're put in the side room, if they know they're going to die, they don't know everyone's going to die. They do move them, so you're not just sitting next to somebody who dies....... There's nothing worse than somebody dying and everyone listening to their business behind the curtains. You feel like when the curtains are drawn that you're in your own little room, but you're not, and everybody can hear you.

Ann's accounts contain some statements which seem to be contradictory. For example, at one point it became clear that far from being reassured by witnessing others' deaths Ann was actually distressed by her awareness of others dying around her. She said:

> Ann: But I saw a hell of a lot of people die when I was in hospital, a hell of a lot, some very quickly. Some like just diagnosed and dead within a couple of weeks. It really opens your eyes.
>
> Catherine: How does that make you feel?
>
> Ann: It was horrible, horrible, scary, and then of course everyone's sort of walking round on tip-toes cos they didn't want to hurt anybody, or didn't want to say the wrong thing, especially if you know them it's really horrible...... They take them into a side-room just before they know it's going to happen, if they know it's going to happen. And when they take the body away everyone's curtains just get shut, and then the porter comes up and whisks off the body bag and it's all done very discreetly, well not discreetly because you know it's happening, but they don't allow you to see anything. I went up there a couple of weeks ago to see somebody and she died in front of me, that was pretty horrible....One day one of the girls had died and I was going out for the day so they didn't tell me, they waited 'til I got back and then they caught me before I saw anybody else. They said, "Sorry we didn't tell you but we thought it would've ruined your day," which it would have done, which I thought was really nice. I mean they're quite caring.

Ann's description illustrates apparent conflicting feelings about the effects of others' deaths. On the one hand she asserts that it has helped her no longer be afraid of her own death, although she prefers the hospital's policy of (relative) concealment to the hospice's approach; equally she talks about how difficult she finds some things, perhaps because they serve as a reminder of her own mortality.

It became evident that individual's own circumstances influenced how they responded to the news that someone they knew had died. Pat found such news difficult to cope with, particularly during the time she was undergoing chemotherapy:

> I sort of persevered, I think while I was on chemotherapy you feel very vulnerable ....There happened to be three or four people each week someone had died. Each week I went in on a Wednesday someone would say oh so-and-so has died, I think that was about three or four weeks running. With me being on chemotherapy as well, your resistance is a bit low, I sort of thought to myself once or twice is this doing me any good? And yet other weeks you can go and there's no bad news and I come home and think oh it has done me some good to get out of the house for the day.

Perhaps Ann's differing responses to different deaths can also be attributable to variations in her own circumstances. For example, when she was very unwell the process of managing deaths on the ward would merely distress her because they reminded her of her own possible fate, however, on other occasions when she was perhaps feeling slightly 'better' she could gain some comfort from the way in which the hospital ward managed death.

Gail and Rachel did not speak to me about actually witnessing another's death, however, they both referred to the effects of hearing about the deaths of acquaintances. Neither of the two women Gail and Rachel spoke about were particularly close friends, but their deaths still had a considerable impact on them both.

> I think the one thing that hit me the hardest was in '94 when I had my second operation for cancer, my neighbour next door Gwen she was also diagnosed as having cancer and she sadly died and I felt guilty because I'd survived and she hadn't. It just hit me why one and not another? But I did I felt guilty for a little while, but I wasn't close to her or anything I mean it was just neighbours passing the time of day and everything, but it did it hit me, it just seemed unfair..... I remember feeling guilty at the time that I had survived and she hadn't. (Gail)

> I didn't think she was going to die, and that has had a devastating effect on me this time. I couldn't clear it from my mind, and yet I wasn't particularly close to her I only knew her as a work associate from years and years ago. I mean she's 32 and had a 6 year old son, she had breast cancer. So that's one of the reasons I was so depressed this time. (Rachel)

It is clear that the effects of others' deaths cannot be ignored when one is considering the experiences of the terminally ill. It is likely that for Gail and Rachel the deaths of these two women with similar diagnoses to themselves made them realise, or reminded them, that their condition could also become terminal. However, the deaths of others did not only serve to remind respondents of their own mortality, but they also influenced what they hoped their own death would be like.

Doing it my way - a 'good enough' death

In the next chapter I discuss in more detail the way in which a diagnosis of cancer and/or an awareness that one's prognosis is now terminal may affect an individual's sense of self and

identity. Here I am more concerned to address how respondents, perhaps aware of the fact they were now dying, or that their diagnosis of cancer may ultimately mean that they would die, formulated their own ideas of the kind of death they hoped for. When individuals spoke about 'death' they did not necessarily mean the moment when physiological function ceases completely but spoke about it rather as a process, the days, hours, minutes before the point when biological life ends. The Good Death too can:

> ...relate to a fixed moment in time, the death event, or it can refer to the dying process, the complex set of relation and preparations which take place over time. (Payne *et al*,1996,308)

It is this more processual interpretation I employ during my following discussion.

As noted earlier the Good Death - the accepting, peaceful, dignified death- has become, in the main, the ideal *institutionalised death within the hospice movement (McNamara et al,1994; Hart et al*,1998). It is easier to manage 'accepting' individuals than those who constantly deny their dying status or continue a futile search for a new 'cure'. Further, McGuinness (1986) argues that nurses prefer quiet patients to those with an 'overt emotional reaction'.

> Although hospices are committed to allow and enable people to die in a way they want to, it is difficult to die an overtly angry death in a hospice as the hospice 'smile' can be very constraining to those who want to 'rage against the dying of the light'. (Field,1996,260)

In addition to this it seems that the Good Death has to some extent become an organisational proxy measure for good quality care. A Good Death, therefore, is not only perceived as being 'good' for the individual but also for the organisation, its staff and the individual's family and friends (McNamara *et al*,1995).

> However committed to letting the patient die or the bereaved grieve in their own way, most practitioners still have an idea of the good death or of good grief. This may reflect their own ethnicity, gender, social class and age: white, middle-class carers who are part of the expressive generation may well have different ambitions for dying and grieving than do those they care for. (Walter,1994,109)

The point is reiterated by Bradbury (1996), who notes that the Good Death is defined by professionals rather than patients and their families. Problems may arise therefore when the definitions of patients, families and staff vary.

While the Good Death has become firmly established in the literature (Payne *et al*,1996) it would seem that its actual existence in reality may be a little more problematic. Hawkins (1990/1) goes further than this and suggests that there is in fact no such thing as the Good Death and therefore to use the term at all is misleading. However, McNamara (1998) argues that in practice health professionals themselves have much more flexible interpretations of the Good Death than the model would suggest. She argues that health professionals frequently express reservations about the Good Death, if only because they feel that open discussion about death or shared decision making at this time is often practically problematic.

> As the Good Death is an idealised concept which is often unrealised, a 'good enough' death appears to be a far more workable definition with which to link participation in the end of life decision making. (McNamara, 1998)

The 'good enough' death is "as close as possible to the circumstances the person would have chosen" (Campbell,1990 cited in McNamara, 1998), or " a death with integrity, consistent with the life that person has led" (Komesaraff *et al*,1995 cited in McNamara, 1998). The 'good enough' death involves individuals doing things the way they want and taking responsibility for their actions. However, McNamara argues such behaviour is often seen as being negative and a barrier to appropriate treatment.

In this section I also argue that the Good Death may be too prescriptive and a more fluid concept of a 'good enough' death may be more appropriate. Part of living with cancer often means confronting or at least contemplating one's own mortality. However, it also means at times seeing others die. Respondents commented on witnessing deaths either in the hospice or hospital, and they also spoke of the effects of hearing about others' deaths.

> Patients learn from each other not only about dying, but also about the moment of death - a moment that many fear. (Walter,1994,124)

Images of, or hopes for, respondents' own deaths were often influenced by the deaths of other people (family and strangers on wards) which they had witnessed before or during their illness. Like Payne *et al* (1996) I found that some people spoke openly about the kinds of deaths they

themselves hoped for, but others alluded to this by making reference to those deaths which they had seen or heard of, which they thought were 'good' or 'bad'. Payne *et al* list six characteristics of a Good Death as identified by patients themselves: dying in one's sleep, dying quietly, dying suddenly, not being afraid/fatalistic, religious faith, and being pain free. Some of these descriptions are problematic, for example to die 'quietly' may mean different things to different individuals. Although respondents in my own research did talk about the deaths they hoped for, it is difficult to categorise their responses precisely because of the vagaries in definition, and the different emphases they themselves placed on different aspects.

The notion of a 'good enough' death appears to be informed partly by individual's own past experiences, the deaths they personally witnessed, or those they had heard about. Anna had watched her mother die, during the course of both her interviews she talked about the fact she wanted a 'peaceful' death (something she felt her mother's was not) she also wanted it to be 'quick'. She said in her first interview:

> I just hope, I don't want to suffer, I don't want them to see me suffer. I don't want to linger. I mean my mum really suffered the last few weeks. The last six weeks of her life were hell, they really were, and I don't want that, I really don't. I hope that it's nice and peaceful. I hope that medicine's come on enough that it will be peaceful. She was very sick, she was just very poorly at the end, very sickly. I was sick on Saturday, quite a lot, and they don't like to see me when I'm sick you know. I hope that doesn't happen. I hope that it's nice and peaceful.

In her second interview she said again:

> It was hard to watch her [mother] die and that, it's history repeating itself you know, when I look into my daughter's eyes I can see what I must have had in my eyes twenty years ago when I was going through it with my mum.

> I've, I'm coming to terms with it. I just want it be peaceful that's all that's important to me. I just want to be comfortable and peaceful and just right. I'd like to slip away very quietly in my sleep I think. I think that would be easier for everybody and I think it would be better for me, I don't want to suffer, and thankfully they've taken away a lot of the suffering, if I'm honest.

And later:

> I'm still scared. Yes, petrified, absolutely bloody petrified I suppose. But as long as it's peaceful, I don't think, I don't think I'll mind. I keep going back to that, but as long as it's peaceful I'll cope with it. And I'd quite like it to be quick I don't want to, I mean if it was quick perhaps it should have been six weeks ago already, in some ways I wish it had been. But when I say quick I hope that when it comes it's quick

and it gets it over and done with. I don't want to sort of linger for three or four days just hovering between life and death. I'd rather that it was nice and quick and just get it over and done with. So I hope he's listening up there, do that for me!

Edna spent the last days of her friend's life sitting by her bed in the hospice. What she witnessed informed her own thoughts about the kind of death she hoped she would not have. She said:

I don't mind if I have to go, but I want to go with all my faculties that's the only thing I want. [My friend was] reduced to nothing, wearing a nappy, incontinence pads. I thought to myself about the first time about taking my own life if they said to me it was in your head and your spine, cos honestly I don't think you'd see an animal go through that.

Edna was the only person who referred explicitly to bodily deterioration in the latter stages of illness, however, others did speak of a 'dignified' death which appeared to have connotations of being in control of one's bodily functions. A timely, peaceful death was important to Katie, she said:

My biggest fear is not dying, because I do believe there's life after death, you've got to, haven't you? I said to her [home care sister], "My biggest fear is how I'll die." I said to her, "I don't want to be kept alive on wires and tubes and in a hospital, forget that, I just want to die peacefully at home, if there's such a thing." And she said a couple of her patients, you know, carried on the same as you and then the last two days of her life she just said she was very tired and didn't want to get up one morning, and passed away two days later. And now when I get tired I think Jesus I'm getting up!

Dying 'peacefully' was a recurring theme in individual's discussions about their deaths. Again, like the phrase 'quality of life' individuals did not define what they meant by peaceful. Its usage appeared rhetorical, people used the term but glossed over its meaning. This is partly explained I feel by the fact that the 'peaceful' death is the kind of death society appears to hold as an ideal, indeed it is a characteristic of the Good Death (McNamara *et al*,1995). To this extent then it is not surprising that respondents also concurred with dominant societal views. For example, in her first interview Sarah said:

I thought, well if I'm lying there and they obviously know that I'm on my way out then they'll make me comfortable kind of thing, because then I'll just probably nod off. I thought to myself I hope that I just nod off kind of thing.

Again in her second interview she also referred to similar hopes.

I thought, that's alright because if I'm feeling low, when you do feel low it's easier, I mean you're more peaceful, and it's more peaceful for you to drift off and go to wherever you go. So, I think I'll be alright about the actual dying.

Although respondents discussed what they hoped their deaths would be like, there appeared to be a realisation or an acceptance that ultimately their deaths and the manner of their dying were out of their control. This acknowledgement of their own lack of control over this particular part of their life is also apparent from the following accounts. Both Anna and Roger mentioned that they would prefer to die at home, however, both acknowledged that this might be taken out of their hands in the event.

> I'd prefer to be at home always assuming that it's practical. We literally won't make any decision, if indeed it is my decision, about that until we need to. I'd prefer to die at home, but if it in anyway puts anybody else out, I mean if it's easier, better to be at LOROS, then so be it. (Roger)

> They [family] want me to be at home, I'm not sure, it will probably be taken out of my hands. I think you know, I mean if I'm going in for something and I'm ill when I'm there it might be that I just don't come out, or it might be that if I'm at home I never get up there in the first place. (Anna)

It is interesting to note that they were both prepared to change and alter as the situation dictated, this would suggest that their hopes for their own death were reasonably fluid and flexible.[5] Such flexibility is not accounted for within the Good Death model, which appears to be much more prescriptive. Given this it would seem that the term 'good enough' is more useful in describing individuals' own thoughts and feelings.

Dying at home has become another ideal associated with the hospice movement and an implicit characteristic of the Good Death. However, dying at home is not always possible in terms of the physical care an individual may need in the latter days of their life, nor is it what everyone wants. Both Sarah and Gail did not want to die at home and tried to explain why they felt this way:

> Just my mum saying to me, "Do you want to die at home?" And I don't think I want to die at home, in my bed because like say if Alex [her son] comes in and I'm laying there dead, it can't be very nice for him to actually see it, or any of the children for a matter of fact. I'd rather be in hospital.... I think it would be easier for my mum if I

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[5] In the event both Anna and Roger did die at home

was at home. But once she said it to me, I thought, no I can't die at home. The thought just didn't appeal to me. (Sarah)

I want to stay here [at home] as long as possible, go in if they need to change my treatment of whatever. Then at the end, you know, I think it would be better to go in at the end rather than be at home. I don't know what the family think, but I think it would be better for them. I think if I was here it would be a bit, I don't know I can't explain. I think it would be better in the hospice but we'll have to wait and see. (Gail)

A Good Death is one in which the individual is aware, accepting and has made preparations (McNamara *et al*,1995). While many respondents did exhibit these characteristics they also remained fearful. Fear is something which the Good Death does not seem to incorporate. Individuals, in general, accepted the fact they were dying, but remained frightened at what this actually meant. This would seem to be similar to Weisman's (1972) concept of 'middle knowledge'. Individuals spoke openly about their awareness of their diagnosis and prognosis, and planned their funerals; and yet at the same time they were still fearful of the reality of death. They approached their death with a degree of acceptance, and yet remained hopeful that modern medicine may come up with a 'cure'. Anna said:

When I stop to think about it it's very frightening to think that you're coming to the end of your life.

Anna's greatest fear was being buried, in particular she was worried about whether she would really be dead.

I hate the thought of being shoved six feet under in a box, but I'll have to believe, I hope that I won't feel it or anything. I don't know, I hope so. I'm nervous, I'm frightened. I'm frightened of dying I don't think anybody could say they weren't.... I hate the though of being put in a box, and in the ground. I hope it's true that if there is something you've already gone by that time, and you really do leave a shell behind. I get very cold, I hate the thought of being buried, I really do, so in my mind I like to think that by then I would have gone on to the next thing.

I'm not afraid of dying. I might be as the time gets nearer I think this time, I don't know I can't explain it, I suppose you get used to the idea don't you? Well, not used to it, you get in tune for what's going to come, what's going to happen.

Individuals often worried about their physical deterioration. Liz said:

I worry about what's coming next for me. What physical symptoms will I get next? Wonder whether they'll be, whether I'll be reliant on him [her husband], for my personal things you know. I'm looking after myself, I'm strong enough to look after myself at the moment, but there will be a time when I can't do that sort of thing for myself, I don't like to talk about that. Because I think it worries him that he might

not be able to cope with that. Although they [the hospice] said that they don't think that will be the way, but you never know do you?

Katie was also concerned about her physical deterioration, but unlike Liz was reassured by what her GP and Home Care Sister said:

> I'd been feeling down, but I'd never thought about it before, it's always something that you know's going to happen, I'm not frightened of dying. I'm not frightened of dying. I was very concerned about the way I was going to die, not actually dying, but [the home care sister and GP] have said that they'll be there for me and they'll do the best they can to keep me at home. They're not saying that they will, but they'll do their best. And I know they'll do their best for me so that I won't be in pain. So you couldn't ask anymore from a human being than that, so that's good.

Individuals were also worried about becoming a burden, such feelings obviously link with Katie's comments earlier relating to her hope that her death would be timely. Both Liz and Rachel commented on worrying about this aspect of their future:

> I don't want to be a liability, nobody likes to think that they can't cope (Liz)

> I don't want to be a burden to anyone, you can only use the telephone so much and you can only look at the television so much. You're just literally sitting here counting the minutes to when he's [husband] coming back, and then when he comes in it's so dashed because he's got to get back to work. I mean I'm aware of that, and I don't want to intrude into that, and I think if only I could do something. (Rachel)

As Gail commented earlier (P130) as different treatments were tried and failed so an individual's hope began to decrease. As Ann's treatment progressed this hope was replaced by fear, she said:

> They were very, very optimistic right at the very beginning, it was like 75% chance and things like that which is quite good odds really. And I took that as yeah they can get rid of it. But when it came to Christmas, I had a bone marrow transplant the odds were 50%, I shouldn't have asked really, but I did, and they told me, and 50% chance is really not very good in my eyes and that depressed me. And then when I relapsed six months after that, so that was sort of June, July this year, the odds were down to 35, and that's how I am now and that's not very high odds.

And later:

> And it's a gut gut feeling and it's really horrible feeling that you have got a terminal disease, or that it could be terminal.

Given the fact individuals did have fears and doubts about their deaths, and the manner of their dying the concept of the Good Death would seem to inappropriate. McNamara *et al* note:

> [Some] nurses are more concerned to allow for flexibility and for patient autonomy as Linda's [a respondent] opinion shows: 'We always seem to be looking at the Good Death from the nurse's perspective, rather than the patients...what are the patient's

expectations...We need to give people permission to make their own decisions."
(1995,238)

Flexibility is clearly important. Although respondents did appear to concur with some aspects of the notion of the Good Death there were some discrepancies. Individuals in this study, although aware of their diagnosis, were still able to both accept its inevitability and deny it (cf. Dumont & Foss,1972). They were aware and planned for it but were also fearful of what might be ahead. Similarly, their descriptions of the kinds of deaths they hoped for often had similar characteristics to a 'dignified' death associated with the Good Death. However, individuals' own emphases varied - for some a 'peaceful' death was of paramount importance, others were more concerned to have a 'timely' death in control of their bodies and aware of their surroundings, for others a 'quick' death was most preferable. Within these adjectives there exists a variety of different interpretations, personally relevant to each individual.

A Good Death may be the death we all ideally hope for, but faced with the reality of one's own mortality and an awareness of one's own physical deterioration and decreasing limitations it would seem that one's hopes may become less prescriptive; they are capable of changing and adapting as the situation requires. Such individual variations suggest the need for a more fluid concept. As I have noted in Chapter 1 Weisman (1988) suggests that the hospice movement attempts to ensure that each individual has an 'appropriate death'. His definition would appear to have similarities with the notion of a 'good enough' death.

> In effect an appropriate death is one we can 'live with'. It represents a significant, if not predominant aim for the hospice program.... But most deaths like most lives and norms of most people, are mixtures of good and bad, somewhere in between equivocal in varying degrees. (Weisman,1988,67)

This point Weisman makes is important. While some individuals will have no choice and will die a difficult death, their physical state out of their control, others, by contrast, will choose to not fully adhere to expected norms, the notion of the Good Death an anathema to them. I believe, given respondents' accounts, that it is likely that many individuals' deaths will fall somewhere between the Good Death and 'raging against the dying of the light'. Individuals have their own

hopes and fears about their dying, these may or may not change over time and in different circumstances; they hope that their death will be 'good enough'. Such flexibility is hardly surprising given the tensions and difficulties individuals face during the course of their illness, compromises are made throughout on many different things, dying is yet another. Respondents discussed what they hoped for (usually in line with dominant models of the Good Death) but equally they acknowledged, accepted and sometimes feared that this may not always be possible in the event. Such flexibility I would argue is not apparent in the Good Death, therefore it would seem that the notion of a 'good enough' death is what is both more appropriate and realistic. A 'good enough' death is flexible, it is a death which although perhaps not 'ideal' the individual can feel comfortable with. It is a death which allows for individual biography, character and all the vagaries which go with this.

> However many dying people I've known, this person is dying for the first time and I don't know what they need: everyone has different needs. You must hold your previous experience of dying patterns very lightly, so if they prove incorrect for this person you can shift very quickly. (Frank Ostaseski, administrator, Zen Hospice Project, San Francisco, Interview,1982 cited in Walter,1994,108)

Each individual's death is personal and unique, as are the hopes and fears they associate with dying and death. A prescriptive, rigid Good Death model clearly cannot fully account or allow for variations or personal idiosyncrasies. Therefore rather than striving for this there needs to be a move to alter current dominant discourses within palliative care and allow the more realistic and achievable concept of a 'good enough' death to prevail.

Chapter 6

Cancer, Dying and Self-Identity

In this chapter and the next I consider the impact an initial diagnosis of cancer, and later a terminal prognosis, had on respondents' lives. In Chapter 7 I explore the ways in which individuals learnt to manage their cancer, and later dying, status. However, in this chapter, I look at how respondents reacted to their initial diagnosis, and discuss what they felt cancer symbolised to both themselves and other people. I also consider the impact of cancer on significant others, and individuals' hopes and fears for those they would leave behind after their death. In this chapter I am concerned to address the ways in which cancer, but more specifically dying, affected the normal everyday lives of individuals. I look at the changes respondents discussed which occurred in both their daily routines and in their relationships with others. I suggest that cancer and its association with death often has a negative effect on an individual's self-identity. People in this situation often feel stigmatised by others perceiving that the roles and identities *they had prior to diagnosis* have been, or are being, eroded and devalued because of their new status of cancer patient.

Images of cancer and their effects on respondents' experiences

Before beginning a consideration of respondents' experiences it is useful to note what they said about cancer, their own views and understandings of the disease as well as their perceptions of what others thought. Cancer often evokes feelings of dread in people because of its association with pain, difficult treatments and ultimately death. (MacDonald,1988; Marten & Davies,1990; Weiss,1995; Colyer,1996). Not only this, but like other chronic illnesses, cancer often has an "insidious onset", it does not "break out" but "creeps up" on the individual who may be unaware there is anything wrong (Bury,1982,170).

> Cancer comes suddenly and unexpectedly. There is little chance of observing it yourself in the early stages. Cancer has a tendency to spread to different parts of the body. In this way the disease becomes something which seems impossible to control

and in comparison with many other diseases it stands out as unusually menacing. (Cannon,1988,128)

Given this, it is not surprising that today cancer (and latterly also AIDS) seems to be regarded as the most feared death in modern western societies, the modern equivalent of leprosy and tuberculosis (Sontag,1991). Nor is it surprising that a diagnosis of cancer has profound effects on individuals and their families (Smith,1990).

> Having cancer changes everything. What that little six-letter word, that incomprehensible diagnosis, that terrible thing that you thought only happens to other people really means is that your life will be inexorably altered. Nothing, your daily routines, your relationships, your beliefs or your future will ever be the same again. (Eick-Swigart,1995,41)

Historically, cancer was always associated with death, mentioned only in hushed tones (Young and Cullen,1996). My respondents commented on this themselves:

> It's just a scary subject, cancer, it used to be called the Big C, no-one ever used to say it did they? (Ann)

> As kids the word cancer was such a taboo word, years ago you didn't mention it. It was an awful word, whispered, cancer like, it was said in that kind of mouthed whisper. (Pat)

> Perhaps because of the age I am, God, you said cancer, you're going to die aren't you, years ago that is. If you said, "Did you know that so-and-so's down the road's got cancer?" "Oh, they ain't got long then." And a lot of people I think still tend to live in that field, perhaps people can't help thinking that. (Gaynor)

It is interesting to note that while respondents appeared to associate these attitudes with the past, it would seem that at times the actual word 'cancer' still presented difficulties for both other people and respondents themselves. Heather said:

> She [sister] always says about the 'illness', she won't mention the word 'cancer'.

'Cancer' it would seem is a stigmatising label, it confers discredit on the individual and may in turn limit their capacity to participate fully in normal social interaction. Ann implies that she herself has some difficulty with the word 'cancer' when she comments that she likes the fact her cancer has a specific name, 'Hodgkin's Disease'. She said:

> I don't go around thinking I've got cancer....the actual word cancer doesn't go through my mind very often. It's just this disease.... I don't call it cancer, cancer, cancer, it's Hodgkin's or the disease. Like if you've got lung cancer you've got cancer and that's it, but it's nice that it's got a name, crazy!

Using the term 'Hodgkin's' may also have another benefit in that others may not necessarily know what it means, and for a time at least it may be possible to avoid disclosing her status of 'cancer patient' to others. Cannon (1988) notes that her respondents referred to 'cancer' as being "terrifying", "nasty", "full of death and suffering", such feelings accord with some of the attitudes of people in my own study. Roz said:

> I was terrified of this cancer word, it was like a death warrant...It's a dreadful word, I mean when they said it to me I can't explain, it was like my body, I can't explain how my body went when they first told me.

However, such a response is not necessarily reflective of everyone's experience. For example, Katie found other people's difficulty with the word 'cancer' ridiculous, she said: "...to me it's a word 'cancer', it's like saying 'cold'." Despite the fact that individuals often commented on their belief that modern medicine had made considerable advances in the treatment of cancer generally, their initial feelings after diagnosis were still of dread. Rebecca said:

> In the early days when they first told me I was doing all the usual things like writing my will out on toilet paper because I couldn't find any other paper and I wasn't going to be alive tomorrow to go down to the shops and get some! Stupid things like that.

When I spoke with individuals they were clearly reflecting on something which for some had occurred months, or even years ago. Given this, with hindsight, they often reflected on how the experience had not really been as bad as they had anticipated. Liz and Gail said:

> It was one of my worst fears, like everybody the word cancer, oh it's terrible isn't it? But really I mean, it is terrible, it's terrible for me, but it's not as terrible as you think really. (Liz)

> They automatically think death warrant don't they? But it isn't always I've had another 5 or 6 years out of it, so I haven't done bad. (Gail)

In addition to being associated with dying and death, 'cancer' also conjures up other physical images for many people. Katie felt that others expected her to have some outwardly visible sign that she had cancer. She said:

> One of the stupidest things that people say when you've got it is, "But you look normal". I think, "How're you supposed to look? Do you wear a cross and garlic and put a stamp on your head unclean?"

Cannon (1988) also notes that other people often expect those with cancer to be immediately recognisable from their physical appearance. For example, a woman with 'rosy cheeks' in her research was felt 'not to look like' she had cancer. Similarly, Weiss (1995) asserts that others find it confusing when people look 'well' but they have cancer, because this goes against what is expected. This accords with my respondents' accounts, many people appeared to expect them to look 'ill':

> I think they expect me to look like I'm ill, they expect me to have grown another head or something. Or sometimes they'll think, "Well, she doesn't look like she's ill, what's she moaning about?" (Sarah)

> When we went to Birmingham a couple there said, "Oh, you do look well!" And you think, "Well what do they expect?" (Gill)

As an individual's prognosis worsens it is more likely that they will begin to fit more stereotypical images. However, at other points, outwardly there may be little evidence of their diagnosis.

Another image of cancer which respondents alluded to was that a person with cancer was viewed as being 'unclean', or potentially contagious in some way. Ann and Roz both commented on how it was not only others who appeared to view them in this way, but they themselves at times felt 'dirty', beliefs which were sometimes also reinforced by the actions of others. They said:

> When I first come home I had this thing that I've got cancer and it's a disease and I'm not a clean person anymore......I went to my sister's and I thought she's going to be funny about me using her bathroom. (Roz)

> I felt dirty that was the worst thing. My sister proved that just after I got diagnosed, I'd gone to her house and I 'd had a bath, and everything I touched she threw in the washing machine. She wasn't doing it secretly, it was like, "Can I catch it?" Kind of thing. (Ann)

This notion of being 'unclean' would seem to imply that individuals may in some way have the capacity to infect others. A respondent in Young and Cullen's (1996) research said that she felt like a 'leper' when her friend refused to have a drink from the same cup she had previously used, because she feared that she might 'catch' cancer. Individuals in my research also said they felt that others sometimes perceived them as a source of contagion.

> I always feel, I don't know if I'm right or not, but I always feel that people don't want you to touch their babies. I actually said to a friend, "You know the baby can't catch anything from me don't you?" (Ann)

> But ever since I've had cancer I've been banned from seeing her great-grandson, "Well, ducky just in case he catches it." I said, "Look it's never been proven that you can catch it. Do you think I'd go near my children or my husband?" "Well ducky, we won't want to take the risk." (Katie)

Although respondents suggested that they found the attitudes of other people ridiculous, at times they themselves also seemed to accord with such views. In Katie's quote this is apparent from her comments that there is no 'proof' that someone can 'catch' cancer, suggesting that it might be possible. Similarly in the next quote despite knowing she was not infectious, Ann was concerned when anyone came into contact with her blood:

> I'm still funny about my blood if I cut myself, and anybody touches me, it terrifies me. It just frightens me because I know it's a blood disorder I've got and I don't want people touching my blood.

Even when individuals suggested that such beliefs were rather irrational, they still continued to inform individuals' feelings and actions in some way at certain times. However, such feelings are not unusual:

> ....even though they were well-informed about the medical notion that cancer is not contagious, never the less they took care not to 'endanger' other members of the family. (Weiss,1995,15)

What such attitudes suggest is, that while individuals were indeed aware of the medical 'facts', at times pervasive lay images of cancer and its imputed infection were still influential. This is perhaps most usefully understood by considering again Cornwell's (1984) 'public' and 'private' accounts. In more 'public' accounts, when there is a need to reassure or convince people of the 'facts', individuals subscribe to accepted medical discourses. Although within the interview setting respondents were clearly presenting another 'public' account there was often either clear reference to, or suggestion of, other more 'private' accounts. These accounts seemed to have their roots in more popular images of cancer and its causes.

Often respondents, particularly the younger ones spoke of others reacting with surprise and incredulity when they discovered their diagnosis. Sarah said:

...some people say, "How come you've got it? You shouldn't have it." You know you get a lot of that off people, off like friends, and like parents in the playground who I speak to and that. "You shouldn't have it, you're too young to have it." But no-one's too young to have it really, it's just not common in my age and people younger than myself, is it?

It was felt by some that it was 'unfair' for younger people to be diagnosed with cancer, because they still had socially valued roles to fulfil in their lives. For example, Edna said of another two respondents:

Sarah and Ann are so young and have got children and I think, oh it's so unfair. I've seen my family, my boys are grown up and I've seen the next generation, but they won't see that and I think that's unfair, but life's not fair anyway. It's the children that get to me, I mean these children are not going to have a mum and you need your mum, especially little girls, and that's hard.

A diagnosis of cancer, like other chronic illnesses, can disrupt an individual's 'expected' life-course.

Chronic illness is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves a recognition of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others. In addition it brings their families, and wider social network face to face with the character of their relationship in stark form, disrupting normal rules of reciprocity and mutual support. Further, the expectations and plans that individuals hope for the future have to re-examined. (Bury,1982,169)

A diagnosis of cancer therefore presents new dilemmas and challenges for individuals, it can have profound effects on the individual's self-identity. Clearly cancer does change someone's life irrevocably, it affects their physical body and it alters the nature of their relationships; change, however, is never only negative and individuals did point out positive aspects to having cancer, which I shall discuss in the following chapter.

Invaded and diseased – The dying cancer body

As I discussed in Chapter 1, self-identity is not 'given' but is dependent upon the reflexive reordering of an individual's biographical narratives (Giddens,1991), and central to this process is an individual's embodied biography (Mellor & Shilling,1993). Given this, it is important to consider respondents' bodily experiences. Within the context of my own research the body endured both the cancer and its treatments, consequently respondents' expectations of their bodies

changed. As noted earlier, cancer is often of an 'insidious' nature, 'creeping-up' on the unsuspecting individual without warning. (Bury,1982). This obviously has consequences for both the individual's bodily experience, and their sense of self-identity.

> The body which had been the kind friend for so long, and given so much pleasure, had turned in to a stranger, even an enemy, and was making itself felt almost as though it was an alien creature, bringing an awareness of capacities they did not know they had until they lost them. (Young & Cullen,1996,39)

Ann Dennison (1996) in her autobiographical account discusses how after her own diagnosis of ovarian cancer she felt 'let down' by her body:

> My body had let me down again. I couldn't trust what I felt. My experience so far had led me to believe if I felt ill I was ill. Now I was learning you could feel quite well yet be so ill you might die. (Dennison 1996,25)

Ann and Sarah both had similar experiences. Sarah felt unable to concur with her doctor's advice to 'listen to her body' because it would 'tell' her when her condition was worsening. She felt this because the last time she had been told her cancer had spread she had been unaware of any physical 'signs'.[1] Similarly, Ann, felt 'let down' by her body, because looking 'well' meant that she found it difficult to convince others (including medical staff) that she could still be deteriorating.

> I wasn't poorly or anything like that, which is a bad thing really, even now the doctors'll say to me, "You're so well, there can't be anything wrong," but that's not true, because it's spread through my body while I've been well.

Both Ann and Sarah knew that their bodies did not always make them aware of the advancement of the cancer, and consequently could not be trusted to give them accurate messages. However, others were able to trust, and hence 'listen' to their bodies . It was the body which at times dictated when an individual 'had had enough'. For example, Rachel's decision not to have any more treatment was based on what she felt physically:

> I'd got the third [chemotherapy session] booked and I thought, my body can't go through this again.

As mentioned earlier the body is important to the construction and maintenance of self-identity, having a 'sick' body therefore had profound consequences for some respondents. Roz continued

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[1] See Chapter 4 p113 for Sarah's verbatim quote

to perceive her body as 'sick' despite initially being told that her hysterectomy might in fact have been curative.[2] This perception of having a 'sick' body was very important in influencing her own view of herself as someone who was not 'healthy', she said:

> I've got this thing in my head, I'm not healthy. I can't say to anybody I'm a healthy person because to me I've got a sick body, even though they're telling me that the cancer's not there anymore.

At times it is the case that outwardly it is difficult for others to tell that an individual has cancer, thus allowing them, for a while at least, to 'pass' as 'normals' (Goffman,1990b). On other occasions some aspects of the disease and its treatment, for example, weight loss, skin discoloration and hair loss, make this difficult, if not impossible. Specifically, as I discussed in the last chapter, respondents spoke about their anxieties at losing their hair after chemotherapy. Ann said:

> It's a very stressful thing losing your hair, it's horrible, and it's the fourth time I've lost it now. It's not nice. It doesn't get any easier really, but you learn to cope.

Having no hair is a visual mark of the fact that one has cancer (Fife,1994). Further, hair is often an intrinsic part of one's body image, therefore the loss of hair will often result in a change of body image and related to this one's self-identity.

> I would look different. I would look like a cancer patient. Day in and day out it would remind me and everyone else. I had only just fully gone back into the world, other people's reactions had always been closely related to the fact that I 'seemed so like my normal self'. Now I wouldn't be anymore. (Dennison,1996,26)

Pat felt that the changes in her body shape which occurred as a consequence of her cancer were another physical 'sign' which distinguished her from others, and reminded both them and herself of her cancer status. She said:.

> I've got a constant reminder of it whenever I see a silhouette of myself, my back's going over like this. I'm sort of on an angle so physically it's a reminder all the time.

It is important to note that while individuals did speak specifically about their deteriorating physical body, it was more common for them to speak of the consequences of this deterioration and how it affected their lives. Decreasing physical ability meant that individuals had to pay

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[2] Roz died shortly after my fieldwork ended.

attention to their bodies because it dictated what they were, or were not, capable of undertaking during the day (Forsyth *et al*,1984). The physical effects of their disease often limited or prevented respondents participating in the activities they had prior to their diagnosis. For example, their physical body was no longer able to do certain chores or tasks. Changes in one's bodily capabilities, as I shall discuss in more detail later, can cause changes in identity and feelings of self-worth (Hinton,1984; Mathieson & Stam,1995).

One aspect of respondents' bodily experience of their disease was their perception of cancer as something 'foreign', 'unwanted' and 'invading'. Such usage of anthropomorphic metaphors is not unusual, for example, Forsyth *et al* (1984) note that individuals with a chronic illness will often personify their disease; similarly Tait (1990) refers to her respondent, "R", referring to her cancer as an "it" or a "thing".

> ...the growth is inside the body, where there is something like a 'weed' or dirt that threatened to burst forth. The growth is viewed as an entity in its own right, and it is referred to in a personified form. (Weiss,1995,20)

Katie referred to both her belief in fate but also, more significantly at this point, 'the cancer' doing what it wanted to, thus imbuing it with the human capacity to choose a particular course of action:

> [The consultant] told us a year, though nobody's God, could be less could be more, that was last October. So, whether it's October, or whether it's Christmas, or after Christmas, or the summer, I do believe in fate I think, what's written down will be, what will be will be. I don't think it makes any difference what medication or what you do, or what you're on, or what you don't do. I don't think it makes any difference, apart from pain, but actually cancer, I think it'll do what it wants.

Such an image of cancer as something out of the control of individuals frequently reoccurred in other respondents' accounts. Its 'uncontrollable' nature was also often linked to other metaphors, for example both Ann and Pat visualised their cancers as physical beings which were 'invading' their bodies:

> Nightmares, really, really horrible nightmares, little green goblin men. Someone told me that everybody's got a visualisation of their cancer, and mine's little green men running through my veins, with it being a blood thing, and they just horrify me at night, come out and chase me and do all kind of horrible things to me. (Ann)

> It's a quick growing thing this one and it's getting worse and worse, it's like this
> thing that goes out like that, with these little fingers reaching out to your organs and
> things. (Pat)

In a related use of metaphors, respondents also spoke about how they felt they were 'losing' and

the cancer was 'winning'. As illustrated throughout the last two chapters 'control' was a recurrent

theme in respondents' accounts; they often felt they were 'losing control', or alternatively that

they needed to 'maintain control' over their cancer.

> I'm losing control I'm getting weaker. Every time I go into hospital I go home that
> much weaker, and this worries me. I'm out of control, I don't want to be out of
> control. (Liz)

> I mean it's on the cards and it's something we're living through, or trying to live
> through. I mean it takes over your life that's the hard thing. It totally takes over my
> life this cancer now, and it never used to. (Anna)

However, it was not only the actual cancer which was viewed as 'invasive', but actual treatments

designed to be of benefit were sometimes also seen in the same way. Karen said:

> I think I'll be more in control when I've finished the chemotherapy... I feel at the
> minute that there's something else in my body at the minute.

Cancer then can be seen to be responsible for different 'invasions': it invades cells and organs,

which in turn requires that the body must then endure 'counter-fire' from surgery, chemotherapy

and radiotherapy. However, it was not only the cancer's physical invasion of the body which

concerned some people, respondents also spoke about how it 'took over' their lives in another

way, by always maintaining its presence at the 'back of their minds'. Those respondents who had

a history of cancer in the family noted that it was something they had always, to a lesser or greater

extent, been aware of. This was the case for Pat:

> It's one of those things that's in the back of your mind when you've got a family
> history of cancer, it is sort of in the back of your mind.

Roz and Edna's experiences were slightly different. Edna had been 'in remission' for a number of

years, and Roz had recently been told that it was hoped that her hysterectomy may have been

curative. Despite this, during the course of their interviews both women frequently spoke about

how they were 'waiting' or 'expecting' their cancer to 'come back'. Roz said:

> I've got this thing that I'm not healthy anymore, I'm going to end up dying of cancer,
> and I'm not letting myself be rid of it. I feel it's going to come back and it's going to

be my death warrant, I'll die of cancer, I'm not thinking I'm going to die of anything else, just cancer.

Thus, although physically perhaps in a more advantageous position to other respondents, cancer still continued to inform their thinking and view of themselves and their bodies; they were not 'in control', their cancer was.

Sontag notes that "militaristic hyperbole" (1991,86) is commonly used in discussions about cancer. As noted earlier staff themselves sometimes employ such metaphors when they encourage patients to 'fight' and 'battle against' their cancer. Lay accounts of people's experiences of chronic illness, or even death announcements in newspapers, are often littered with heroic imagery - 'bravely fought', 'sadly lost their battle' (Seale,1995). Gail's words therefore may be understood within this context of providing (albeit perhaps unintentionally) an 'heroic' account of her own cancer experience. She said:

I fought it with everything I've got in the beginning, I think I fought it all the way, but as time's gone on I've know that I'm losing, but I don't feel that I'm giving in to it, and I still feel that I'm giving it a good run for it's money. I won't give up easily.

Such an account obviously stresses the fact that Gail feels she has done everything she can in the face of her cancer, more subtly it reaffirms the fact that she is not 'allowing it to win', or 'giving in', behaviour which, as already noted, would be unlikely to be viewed as being 'appropriate' by either staff or other lay people. Gail's account is perhaps better understood if one considers the fact that Seale (1995) argues that although dying may indeed present new dilemmas for maintaining self-identity, individuals facing death in contemporary western societies do have opportunities to still construct meaningful narratives.

Understood until now, then, as a particularly bleak area for maintaining the integrity of self, dying for many (but not all) individuals can nowadays be successfully incorporated into the process of reflexive formation of self-identity described so evocatively by Giddens (1991). (Seale,1995,598)

This point is particularly pertinent to my discussion in the next chapter when I consider the ways in which respondents negotiated and managed their self-identity at this time.

Cancer, dying and relationships

In an autobiographical paper Eick-Swigart (1995) notes that after a diagnosis of cancer all past, present and future relationships in an individuals life change; others no longer seem to react in the same way:

> Some friends and relatives make the pilgrimage, convinced that you are on your death bed and then are taken aback by how good you look, others come in deaf. You see it in their eyes; you are a reminder of death. They talk in low whispers and stand by the door, as if your cancer could be caught. Others come armed with an arsenal of questions... Some friends don't come at all. And when you call, they talk about the weather, the last movie they saw, and they never mention your illness. (1995,41)

As already noted cancer accounts for the largest number of deaths in women aged 25-64 and the second in men of the same age. These individuals are more likely to have dependent children and living siblings and partners (Seale,1989,1991a). Given this they are unlikely to experience their cancer in isolation, therefore it will have some effect on other family members (Fife,1994).

> Diagnosis of cancer presents a crisis in the life of the patient and her/his family. The uncertain prognosis of the illness necessitates coping with the need for ongoing treatment, the possibility of additional surgery, the potential for spread of malignancies, and the possibility of death. Many patients are forced to adjust to a change in lifestyle and role functioning. (Wood & Tombrink,1983,45)

All respondents spoke about how their life had changed as a result of their cancer, specifically within the family unit they often noted how their roles and responsibilities had changed. Such limitations to their normal social roles obviously had an impact upon respondents' self-identities:

> A patient who lives with cancer finds herself in a nexus of dynamic psychosocial events. These events often result in reports of loss of productive functioning, financial strain, family stress, personal distress, stigma and threats to former self-image. (Mathieson & Stam,1995,287)

Sometimes rather than being negative changes, as implied above, alterations to relationships and roles were felt to be positive. Fife (1994) notes that the partnership relationship in particular is often reported to be strengthened after a diagnosis of cancer. This also appeared to be the case for my respondents. Roger and Sarah said:

> Our relationship has improved no end. I imagine it does with most families.... I can't even remember being this close when we got married. It changes, well for us anyhow, it has changed that much. (Roger)

> It's [relationship] changed, I think we've got a bit closer, because I think things like this do bring people closer. (Sarah)

Although a diagnosis of cancer could be 'beneficial' it could also cause difficulties within relationships. For example, Karen's husband had also been diagnosed and treated for cancer prior to her own diagnosis. For this particular couple the cumulative effects of their diagnoses was sometimes difficult to manage. Karen said:

> It has brought us closer but there are times when we get very frustrated between ourselves because there's so many things that I can't do, and there's so many things that Jim can't do.

Earlier I discussed the physical effects of cancer on respondents' perceptions of their bodies. The invasive nature of cancer, particularly as their condition worsened and they became weaker, meant that often respondents were unable to fulfil the roles and routines they had before their diagnosis; this in turn often eroded identities they held dear. For example, to give up work before one planned is difficult for an individual, because occupation is important to self-identity (Young & Cullen,1996). Rachel, like others, had to stop work, this combined with other aspects of her 'normal' life which she also felt she had lost was difficult to deal with. She said:

> Everything's changed....I was working full-time, my husband and I do dance classes, obviously cleaning the house, taking the dogs out, I had quite an active life. And my job at work is quite a responsible one and I like to keep quite active I hate being on my own, I hate my own company....It's just turned from all go to all stop.

Anna and Roger commented on the fact that within the family unit roles changed, as they became more limited physically. Roger found that initially this was difficult to accept, but he appeared resigned to these changes when we spoke:

> A lot of the practical things I'm incapable of doing, my wife is taking over an increasingly practical role. For goodness sake she even checked the oil on her car the other day - something that's been unknown before!....It seems very strange, I'm about used to it now, the fact that I can't and therefore she has to, but it was a bit of a challenge to the old male virility!

By contrast, Anna continued to resent the loss of her traditional roles, even those she disliked, because they were part of her 'normal' everyday life and thus important to her self-identity as 'mother' and 'carer' within the family unit. She said:

> .....the washing up, and the cooking and the cleaning and that, I don't do it so much anymore, and they're having to do more, and I don't like it, because it's my role. I don't like my husband coming in from work and stacking the dishwasher or unstacking the dishwasher. I've lost control if you like, it's my job not his..... I hated

cooking anyway, so that's been quite easy to give that part up, although funny enough even that I've resented it because it was my job, it was my job to do it all.

Clearly such changes in the nature of relationships coupled with role restrictions can be difficult for individuals.

> Serious illness poses a significant threat to *self-esteem* or *self-worth*, for it frequently threatens the roles one assumes, and it can reduce the individuals social status and threaten relationships. (Fife,1994,313 - original emphasis)

A diagnosis of cancer affects one's ability to fulfil routine chores which consequently affects one's 'place' in the family unit. With respect to this Katie and Ann said:

> I still find it very hard to adjust, I find it so frustrating I could scream. (Katie)

> When I came out of the hospital the whole routine of the house had changed and I didn't feel like I belonged. I felt like I was put in a little cupboard, because if I needed anything and I got out of bed I was told off, so I had to bang on the wall or the floor.....He [husband] wasn't even letting Lisa [daughter] help, he wanted to do it all, and that really hurt, and as I got up over the last few weeks and started to actually do something. I mean the first day I got the hoover out, "That's my job,!" he went, "you shouldn't be doing that." And, I didn't have a place anymore (Ann)

Hinton (1984) notes that individuals living with terminal illness are often concerned about the effects it has on their family, because:

> Along with commonly experienced losses of functioning and increased symptoms, terminal illness confronts the family with the reality and the meaning of approaching death, as well as the need to come to terms with their approaching loss. (Germino *et al*,1995,45)

Respondents were aware of this and they worried about how individual family members would cope, specifically Anna and Ruth, like Dennison (1996), were concerned for their husbands, suggesting that it might be more difficult for the partner who does not have cancer. They said:

> I know what it's like when you're the victim so to speak, and in a way I'm glad it's me and not him, if it was the other way round I don't know how I'd be coping with him. You know if it was him that it was happening to, it must be very hard, harder in a way, I don't know. (Anna)

> It's more difficult for somebody who's looking after you, because it's not happening to them and they've got to watch it happen to you, that's what's a bit more difficult. (Ruth)

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Many respondents were parents and as such were concerned about the implications of their cancer for their children. Ann spoke about how her loss of hair meant that her young daughter suffered at school:

> The first time I lost my hair she [daughter] got a lot of jip from school friends. I wear a hat, it's so I don't embarrass them really, I'd be quite happy to take my hat off but the children get embarrassed and then they take the mickey out of Lisa [daughter].

Another worry for parents was the fact that in recent years it has been established that some cancers may be hereditary. A number of the women involved in the study voiced their concerns for their children, particularly the likelihood of their daughters (in the case of breast and ovarian cancer) also eventually being diagnosed with cancer. Both Rebecca and Anna were concerned that their daughters should be involved with appropriate screening programmes.

> I worry about the effect on them, I keep going on to Kay [daughter] have you had any screening yet? (Rebecca)

> I'm very insistent that Helen [daughter] goes on to some sort of screening programme. That's something that's very important to me that Helen get on to a proper screening programmes because it's rife in the family, and I want her to be watched. (Anna)

During the fieldwork only Gaynor and Anna had actually given blood samples to be genetically screened. Given the fact that respondents with a history of cancer in the family said that to some extent it had always 'been in the back of their mind', it may be useful to speculate on what effect a positive genetic test may have on individuals. Would they, having been confirmed that they have a significant risk of developing cancer in the future, take on that 'status' even before medically diagnosed (Katz Rothman,1997)? More fundamentally what effects would such awareness have on their actions and their self-identity? This was a concern for Gaynor, she wondered whether her daughters would have the test, and if they did, her concern was how they would cope with the knowledge it may give them. She said:

> Now my sister she had a lump removed last September, because there's quite a few of us in the family that's had breast cancer. I've had cancer, my auntie, she died when she was 29, then her mum, then her auntie she had breast cancer.....then my sister...We've had blood tests because it's obviously in the family. I've got four girls, I suppose if I'm truthful with you, and I've said to Ted [husband], that worried me a bit, not a bit, that's a lie it's no good me saying a bit, yeah it does worry me, because when you think I've not only had it once, this is three times and I worry about the girls. I mean, what would you say the law of averages that one of them's going to contract it, it seems a bit high to me, because it's in the family....[But] will they want

to know? You know when they've done this test they've got to make the decision then, that yes they've done this test, what's the average of them going to get it? Then what's the next step? Are you going to take that decision?

Another consequence of having a terminal illness which concerned respondents was how their children would cope with bereavement. Respondents with older children, although concerned to be leaving their children, were able to gain some solace from the fact that they were adults and had others around them to support them in their grief. However, Ann and Sarah had young children and while there were others who were willing to take care of them after their deaths their concerns were of a slightly different nature They were worried that should they die within a relatively short period of time this would affect their identities as mothers because their younger children particularly may not actually remember them. In their accounts below they both speak of hoping that they have 'more time' with their children.

> I keep saying if I get another five years I'll be happy because of my children. It's the kids isn't it? It's not me I'm worried about, I'm not scared of dying, it's just losing your time with your children. (Ann)

> I thought, if I could have another like five years, even five years, then Christopher would be six, the same as Alex is now, and then I'd be alright, I'd be content......I don't mind popping off then because I know Christopher'll know me by then. (Sarah)

Clearly the fact that they may never be identified as 'mother' by their children was difficult to accept. In the next chapter I discuss how they, and other respondents, sought to maintain their valued identities, including that of parent, after their deaths.

Not only were many respondents themselves parents but they were all also someone's child, and more importantly the majority still had parents who were alive. When they spoke about their status as children they often mentioned the fact that it must be particularly difficult for parents to come to terms with the fact that their child will die before them, because this is not something one would presuppose in any taken for granted assumptions about one's life-course. Both Edna and Ann commented on this:

> My dad was devastated and my mum, I think she thought at the beginning my sister had not long died, and I think she thought she was gonna have to put another child in

the ground before she died, because it's not natural for children to die before their parents. (Edna)

It's mummy, it destroyed her, I still feel that I'd like my mum to die before I die, because you don't expect your kids to die before you do you? (Ann)

As a result of such awareness individuals sometimes tried to protect their parents from the truth.

Rachel said:

We tried initially to protect her [mother], of course then it got to the stage when she had to be told, and I must admit I've had one or two tearful conversations.....because when you think about it it's not logic, you shouldn't die before your mum.

The experience of dying before one's parents is clearly age specific, however, in a more general way what these experiences also highlight are the problems which individuals face when something occurs in their own lives which in some way deviates from the 'norm'. It is clear that such experiences are extremely difficult to deal with on an individual basis, but are also difficult to manage in order to limit the potential damage they may cause others.

Individuals are not only located within the family unit but they also have relationships outside it. Therefore, it is not only relationships within the family which change after an initial diagnosis cancer, and later subsequent terminal prognosis, but so too do many friendships (Fife,1994). Again in my study I found that these changes could be both negative and positive,. Both Liz and Gail found that their friends were generally supportive:

You see, so all my friends if I want to talk about it, talk about it. I don't sort of want my friends to skirt around it because they all know what's happening and it's better than sort of sweeping it under the carpet, and just pretending with your friends, because if they're uncomfortable when they visit they won't come again. (Liz)

Lots of good friends, they're all ever so good, supportive, most of them, they don't get embarrassed they can talk about it. (Gail)

However, friends, although perhaps trying to be supportive, could at times also be unrealistically optimistic. Sarah found this to be the case with one particularly close friend:

She [friend] was in the kitchen when I came home and she said, "Well what did they say then?" I said," Oh a few months to two years." And she went, "You haven't got to believe everything they say, you know, they can't actually give you the time."....and that's her attitude she still believes, can't believe that it's actually happening.

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Although for some contact with friends did continue in the same way and frequency as before it was often the case that respondents felt that they were being treated differently. Katie said:

> But people treat you in a different way, "Oh, are you sure you're alright?" "Oh, we think you're very brave travelling." And I think God I'm alright. So sometimes they'd go overboard, you know it wasn't consistent, one day you'd be cooking the dinner and doing everything, and then, the next, "Oh we think you're really brave coming over and are you sure you're alright?"

Such accounts clearly show that at times respondents could have conflicting feelings towards their friends. On the one hand they were grateful to still have their friendship, something which, as I shall discuss, was not always the case; on the other they resented the fact that their friends kept reminding them of their cancer, which thus ensured that it remained an intrinsic part of their interactions with them.

Respondents frequently told me that both their friends and acquaintances were generally aware of their diagnoses. However, Roger and Ruth said they were wary of telling everyone, because they felt that knowing could be a burden for others. Roger said:

> The odd few [friends] know the complete story, we've not told the complete story to everyone, I don't really see why I should burden them with it really, it's bad enough for some of them to know I've got cancer, without knowing how short a time I've got.

However, 'not telling' others has another function, not only does it benefit others, more importantly it maintains the pre-cancer identity of the individual a little longer. A woman with breast cancer in Mathieson and Stam's study said that she did not want her friends to know she had breast cancer because she herself had another friend who had cancer and she said, "I couldn't get beyond that [cancer] to see the person she was." (1995,297). Such reluctance to tell others about their diagnosis can also be seen within the context of what Goffman (1990a) refers to as 'impression management', whereby individuals may seek to present an acceptable public face, that of being healthy. Having to decide whom one tells about one's diagnosis suggests that people regard 'cancer' as having a potentially damaging effect on self-identity; it is this point I turn to address now.

Avoiding the dying, avoiding the subject: Cancer and dying as stigma

Thus far I have concentrated on those relationships which remained relatively unchanged by the diagnosis, yet, even within these relationships I have pointed out that respondents still said they had difficulties. However, other relationships changed completely, respondents spoke of acquaintances avoiding contact with them in the street, and friends and family no longer visiting. Cancer means facing two 'enemies', the enemy within - the actual cancer - and the enemy without - the social stigma (Colyer,1996). At times respondents' awareness of their own decreasing limitations coupled with their belief that they were being avoided by friends and family had a significant effect on their self-identity. It seemed that they felt their cancer had in effect become their 'master status', that is that others apparently reacted to them primarily on the basis of their diagnosis. They felt they were stigmatised (Goffman,1990b). However, an individual's self-identity is multi-dimensional, that is they have a 'simultaneous multiplicity of selves' (Goffman,1978). Emphasising one aspect, particularly one which is stigmatised, means that their identity becomes one-dimensional as other more valued characteristics are ignored or negated because they have cancer and are dying.

Goffman (1990b) identifies two groups of people who are stigmatised - the 'discredited' and the 'discreditable'. The former group have a physically visible characteristic which sets them immediately apart from the rest of the group, for example in the case of physical disability. The second group, the 'discreditable', possess a characteristic which although not physically obvious, (for example, mental illness or a criminal record) would, if discovered, change others' perceptions of them. As I discuss later, the discreditable individuals unlike the discredited can, to a greater or lesser extent, attempt to hide their stigma from others; they manage their stigma by 'passing' as 'normals'. Dying of cancer means that individuals are likely to experience being both discredited and discreditable during their illness. For example, losing one's hair physically sets one aside as someone with cancer (or someone who is receiving 'treatment' for cancer). It is a bodily display, which although possible to disguise, sets the individual apart. Equally as the disease progresses

and individuals lose weight, perhaps become house-bound, their physical appearance changes and managing their 'stigma' may become more difficult. The outward bodily appearance of an individual in such cases is obviously important. As Kelly and Field (1996) note the bodies of the chronically ill have the capacity to actually undermine an individual's role performance:

> ......they may inhibit the capacity to play social roles. The body in chronic illness is thus not just the repository of some real or socially constructed lesion, it is also central to the social process. (1996,246)

Equally individuals living with cancer are also potentially discreditable much of the time, when there are no physically apparent signs of their condition. In these instances they are only likely to become stigmatised when they tell people about their diagnosis and/or prognosis. In such cases their bodies do not 'let them down' in social interaction because they look as 'normals', however, there is still the possibility that they may become stigmatised as others learn of their diagnosis.

Such illustrations may suggest that respondents only needed to manage their stigma when they were in the presence of those who were unaware of their diagnosis. Indeed Goffman suggests that 'stigma management':

> ......might be seen as something that pertains mainly to public life, to contact between strangers and acquaintances, to one end of a continuum whose pole is intimacy. (1990b,69)

However, he goes on to note "one must go on to see that familiarity need not reduce contempt" (1990b,70). I do not suggest that those close to my respondents were contemptuous of them. Indeed, given the accounts I heard this was often far from the case. However, an awareness of the truth, even caring for someone who may be regarded as stigmatised does not necessarily remove the need for the individual to manage their stigma. To this extent then it is clear that skills required for 'stigma management' will vary according to the situation individuals find themselves in. For example, as I have already noted when individuals were still apparently 'well', that is 'discreditable', they sometimes chose not to reveal their cancer status to friends and acquaintances, thus ensuring that their self-identity remained unchanged. Equally, with those who were aware of the 'truth' individuals sometimes engaged in 'covering' (Goffman,1990a). They

made attempts to detract attention away from their illness either by quickly dismissing questions about how they were feeling or trying to continue as 'normally' as possible.

I now turn to address respondents' experiences which illustrate the extent to which they felt their diagnosis had a detrimental effect on their social interactions. Many referred to their cancer 'taking over' both in physical and metaphoric terms. It seemed at times that everything revolved around their cancer, it had to be considered at all times even for the most mundane tasks and they resented it. They commented on how others appeared to perceive they had 'changed' as a result of their diagnosis. Katie said:

> ....you don't get treated the same, you get treated as though you're a bit senile and you're not the same person anymore. The cancer takes over the family, it's the condition it's not mum or Katie.

This accords with the experience of Ruth, a woman in Mathieson and Stam's study, who said:

> I don't want to wear a cancer identity ....I think that your identity is something that you're given by other people and it affects your perceptions of yourself. I suppose to my friends I'm Ruth with cancer, not just plain Ruth. So I think that as part of your identity does change. (1995,294)

Respondents told me that they felt others no longer saw them in the same way as they had previously, they surmised this because some of their relationships appeared to change after their diagnosis became known. Such changes in attitudes towards them were difficult to accept, particularly when they themselves still felt they were, in many ways, still the same people they were pre-cancer. In Lofland's terms it can be seen that respondents wanted to limit the amount of 'space' in their lives which was concerned with dying:

> By space, I refer to the amount of 'area' within what we might conceive as the individual's total life-space he or she chooses to devote to the dying role. What part of the pie, as it were, is to be labelled 'dying'; what proportion of the self is this identity to encompass. (1978,50)

In these instances it appears that individuals were more concerned with their self-identities as living beings. For example, Ann and Gail said:

> I like people to treat me like a normal person, just because I've go this disease doesn't mean that I can't play with their children. (Ann)

> I eat, I drink, I gossip, I curse, I'm still me. (Gail)

It would seem that others found it more difficult to 'see' beyond their status as someone who was dying of cancer; their 'stigma' became their 'master status'.

> Dying was a dominant and central status which was attributed to the person by others and was coercive in its consequences. (Field,1996,257)

One way in which relationships changed for my respondents was that some felt that others avoided them, 'crossing the road' was a phrase frequently used. Roger and Katie said:

> .....the reaction of other people when they find out you have cancer, most strange, really odd. You get some people who will just, you know, rush to you and stroke you and say, oh I've heard blah, blah, blah, and you get other people and I'm talking close friends that will metaphorically cross the road, rather than talk to you, and it's the Big C, it's nothing else, but they cannot handle it. My boss can't handle it, he will do anything but talk about it, he'll walk off in mid-conversation....pick the phone up, will not talk about it. (Roger)

> I think they [friends] all know the prognosis but they don't really know what to say...people'll say the most stupidest things. It's like bereavement, they'll cross the road rather than have to confront you. (Katie)

While avoidance was commonly reported, it should be noted that sometimes respondents also felt that friends and families could be too overbearing. Sarah said:

> Like if I want a drink of coffee I can go to the kitchen and make myself one, where as before its, "I'll do it for you, you just sit there and rest." They seem to think if I sit down and rest that it'll either go away or I'll live longer, but if I get up and start doing things and wear myself out then I'll die quicker.

Both avoidance and 'suffocation' suggest that others no longer perceived individuals in the same way they did before; cancer became their 'master status'. I have already noted that during the course of living with cancer individuals occupied the position of being both discreditable and discredited, and sometimes they were both at any one time. A diagnosis of cancer does not automatically mark the beginning of a continuous physical deterioration culminating ultimately in death, individuals may in fact have periods of 'remission' when they are able to resume and continue activities and roles they had prior to their diagnosis. The unpredictable nature of cancer is itself therefore confusing, one month individuals may appear 'normal', the next 'ill', this obviously has implications for relationships. Ann said she had some friends who never visited her when they knew she was having treatment, but when she was out of hospital, apparently 'in remission', they came round and were able to continue as before. She now resented these friends

whom she had previously thought of as being very close, another example of the way in which her cancer changed the nature of her relationships.

Not only did others physically avoid individuals but also they preferred not to talk about cancer and dying, either avoiding the subject completely, or changing the subject of conversation if respondents began to discuss it.

> I think my husband's a typical man, he doesn't talk about it, he doesn't instigate talking about it, he'll talk about it when I sort of say something to him. (Rachel)

> Most of my friends, they don't want to talk about, they think I don't want to talk about it, they ask me how I am and I say I'm doing this and doing that and blah blah blah, but then they like to change the subject quickly.... I was telling him [a friend] and then, in the middle of me telling him, he got up and went toilet, and then when he came back it was a case of, "Oh, I'm going now." See what I mean? (Sarah)

When individuals persist in trying to talk to friends and family, they sometimes relent and give up because it becomes clear that others are uncomfortable. For example, Liz said:

> I can talk to some of my friends, not all of them... Yesterday, my husband brought my friend from the village, when Dave [husband] wasn't here I said to her, "I don't want to be here," and she cried. So I shut up.

However, the fact that other people did not know how to react when they discovered that an individual had cancer could be used to respondents benefit at times. For example, Sarah found her diagnosis could be used to her advantage when she was faced with a difficult situation.

> I don't mind saying it to strangers when they're being bolshy, you turn round and say, "Well, it's because I've got cancer!" And it shuts them up.

Within the context of my own research it is difficult to know how widespread such physical avoidance by others, or difficulty in conversations, were in reality. In addition, if this did occur it is impossible to know what were the reasons for it. However, whatever the perception of friends and family may have been, what would seem to be true is that respondents felt that others often either avoided them, or felt uncomfortable around them because of their diagnosis. Perhaps this can be partly understood if one considers an earlier section of this chapter in which respondents themselves referred directly to public (mis)conceptions about cancer, many of these were linked

to people associating it with death and hence being afraid of it. Given this it is not surprising that individuals felt that it was their cancer, rather than the inability of friends and family to communicate with them, which caused difficulties once they were aware of their diagnosis. It was clear that for respondents the actual physical effects of their illness, coupled with an awareness of their own decreasing limitations, further reinforced the notion that their illness was in many ways taking over many aspects of their lives; it had to be considered and allowed for at all times.

It is important to note that although others either avoided respondents or avoided the subject of cancer and dying, they were not alone in their avoidance. Abiven (1996) refers to cancer patients withdrawing from people or things they were interested in before their diagnosis. My respondents also spoke about how, at times, they wanted to be left alone and friends and family did not necessarily understand this. Those who did mention this seemed to describe a fluid process, rather than one where they felt they had reached a certain 'stage' where they 'withdrew'; at times they were able to cope with normal social interaction at others they felt the need to be alone. For Anna and Katie it seemed there was nothing that they specifically put their avoidance down to, they said:

> I've got a friend popping in at some stage this afternoon..... [and] I'm not particularly bothered about seeing her, you know. She'll sit and have a cup of tea and it'll pass half an hour, I should be grateful for it really, but I don't want her to come particularly. (Anna)

> I must be getting a bit of a hermit, I'm quite content to sit on my own. (Katie).

By contrast Ann felt that it was the fact she was dying which made her want to 'pull back' from those around her. She said:

> That was the terror I was just dying and I couldn't get it out of my system, and then after the transplant I wouldn't let anybody near me, touch me, cuddle me, I didn't want them to get close to me in case I died, if that makes sense.

Ann also said that the deaths of others had a significant impact on her. Ironically, despite being critical of those individuals who avoided her, Ann herself at times avoided getting too close to those she thought were going to die shortly, or those who had been recently bereaved. She said:

> It seemed at first that every time I made friends with somebody they died, and you go through fits and starts like that, you start talking to people and make really good

friends with them, and then they're dead. You have to come to grips with that and it's hard, and it happens a lot. I think four people died while I was in hospital the last weeks. And, yeah, it knocks you a bit.

And later:

It's hard to make friends when you know, that they're going to go. There was a guy who died about two weeks ago, and I knew he was going to die eventually, he was quite poorly, but you tend to keep your distance, I mean you don't want to get too friendly. And I bumped into his wife, and his wife was having a right old chat, and I was thinking, I don't wanna know, I don't wanna be your friend, because I'm going to have to cope with this as much as you are if I get friends with you.

Such behaviour can be compared with Janis' (1962 cited in Crookes,1993) concept of "Old Sergeant's Syndrome", where battle-weary soldiers refrain from forming new friendships because there is a strong likelihood of those friends dying. In such cases, Janis argues there is a tendency for individuals to isolate themselves to avoid the pain of loss. In this light, Ann's attitude can be seen as a "survival strategy" (Bauman,1992). She herself has cancer which demands a great deal of time and effort both emotionally and physically, dealing with other people's grief would be yet another drain on her limited resources. Avoiding people in these circumstances can be seen as a means of self-protection. Further, by disassociating herself from those who are dying or bereaved she may have been trying to minimise the extent to which she would suffer from 'stigma contagion' (Goffman,1990b). If others were unaware of her diagnosis, or if she managed to at times reassert her more valued self-identities, frequent association with those who are stigmatised might undermine and destroy her efforts.

Just as respondents avoided contact with friends and family at times they also avoided talking about their illness, often suggesting that to do so would be another way in which cancer and dying 'takes over' their lives. With reference to this Katie and Heather said:

I think it's best to be straight with people but we don't talk about it we just carry on with our lives, because I always think if you keep going on about it, it takes over your life and you eat, drink and sleep it, and then I think it's winning. So, I think whether it's called blocking it, or what, the less I think about it the better. (Katie)

I can't bear it when people are sorry. I like people to come and if they want to mention it, to mention it, but I don't like to be reminded all the time. (Heather)

Avoiding the subject can be seen within the context of 'stigma management', because respondents hoped such avoidance would enable them to maintain more 'normal' social interactions. This may also be seen as part of the process of 'role distancing' (Goffman,1978). Respondents did not want to be reminded of their illness all the time, because this only served to devalue and marginalise other more important aspects of their identity. Again, they were trying to limit the amount of 'space' occupied by their dying (Lofland,1978). Individuals also avoided talking about their cancer and dying for other reasons. Some research suggests that such avoidance stems from the desire on the part of the individual to maintain a 'stiff upper lip' (Waxler-Morrison et al,1991; Mathieson & Stam,1995). However, this stands in opposition to Walter's (1994) suggestion that in, what he refers to as, 'neo-modern' death individuals are increasingly encouraged, and coming, to rely upon the support of counsellors and self-help who aim to enable and support them in discussing and exploring their experiences. Other studies have shown that when cancer patients do talk about their illness they are more likely to speak to their partners than anybody else (Germino et al,1995), but they even refrain from doing this sometimes because of the pain and grief it may cause (Hinton,1981; Germino et al,1995). Similarly, in my own research, at times it was not that individuals did not want to, or could not, talk about their illness, but that they felt talking about it with those they loved would be too painful. This is apparent from Ann's comment:

> I can quite happily sit there and chat and laugh and tell her [an acquaintance at the hospital] all about myself, and listen to her tell me all about herself, and it doesn't bother me. But when it comes to somebody who I'm really close to, who I really love, or who I know loves me I can't do it. I can talk to you, cos I don't love you, you're outside the family, but I just can't talk to the family.

She was able to speak to me presumably because she did not feel she had to 'protect' me because she did not love me and therefore her words would not hurt me.

Another way in which relationships change after a diagnosis of cancer is that individuals no longer occupy an equal position, because one part of the relationship no longer has the same capacity to plan for the future as the other. One person no longer has the same future as the other.

Young and Cullen (1996) note that this was the most difficult thing for their respondents to give up.

> Loss of the illusion that life is predictable, which can never be fully removed following the diagnosis of a life-threatening illness, is an important dimension of the loss of personal control. (Fife,1994,312)

I also found this to be the case, both Anna and Liz commented on how they had become envious of their friends' futures, because they no longer had the same.

> No, it's the fact that people have got futures. People will come, I feel it worse when people come to the house, friends, family and say, we're going to do so-and-so next year and it's not until they've left, and I can see them leave that I think to myself, well they've got a future, they're planning. And I can't plan, but there you are. It's not being able to look forward. (Liz)

> I'm jealous of what they're talking about.... I get jealous I think, I'm jealous of it, if I'm honest with myself because they've got what I haven't got. They talk about, "Oh we might go to the pictures on Thursday night," and I probably wouldn't't've wanted to go anyway, but I know damn well that I can't go this Thursday night. Do you know what I mean? I get a bit, not bitter, bitter's not the right word, but I'm envious, I'm envious because I don't want to be poorly, I want to be well, and I'm envious they are in good health. Thank God they're in good health, I don't wish anybody any harm, but I want to be in good health too. (Anna)

Later in the same interview Anna said:

> I'm jealous of them, they don't mean it, I'm sure I would have been exactly the same, they don't mean any harm by it, but I'm jealous, what can I do? I'm jealous of everybody that's healthy and well, not that I wish anybody any harm I must keep saying that, but I'm jealous of everybody, I think, I should think that's normal though, I should think that's quite normal.

Being unable to plan to any significant degree is reflective of a loss of control which places those who are dying outside the more general experiences of the wider community. People do not know what to say because the dying can no longer have the same hopes and expectations for the future which others share. It is, according to Bauman, this lack of a future for the dying which is so problematic and accounts for the apparent difficulty of others in their presence:

> It is not delicacy of manners that deprives us of speech, but the simple fact that, indeed, we have nothing to say to a person who has no use for the language of survival; a person who is about to leave the world of the busy pretence that that language conjures up and sustains. (1992,8)

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The dying as outsiders

Much of my discussion thus far has centred around the fact that a cancer, but also a dying identity is felt to be a stigmatised identity.

> [Cancer] patients quickly come to feel terribly isolated, and this isolation is bidirectional. On the one hand because of their serious illness they experience themselves as removed from the flow of ordinary life...On the other hand they are often feared by friends and family as reminders of mortality. In general social relationships either get better or worse but they rarely remain the same. Many people in the cancer patient's life simply do not know how to talk to the ill, they frequently refrain from doing so and making relationships more awkward and strained. (Spiegel,1990,1425)

Given this it is useful to consider why others appear to find social interaction with the dying so problematic. When people are discovered to be dying, but more specifically when they are discovered to be dying 'prematurely' - which all the respondents in my research could to a lesser or greater extent be said to be - it may be more difficult for those who know them to come to terms with this than had they been older. As noted earlier, dying and death on an individual level are often difficult for people to deal with. Any difficulty is likely to be further compounded if the person who is dying is regarded as being 'too young'. Given that the majority of my study group were in their 40 s and 50s and some way off the 'three score years and ten' society would have us aspire to, the experiences they describe could be argued to be age specific. However, I believe this is not necessarily the case. Rather, the experiences of these individuals were felt more acutely because of their ages. It is likely that all those who are dying may feel to some extent excluded either physically or metaphorically (Blauner,1966; Elias,1985). All my respondents were socially active before their diagnosis, some worked, they were all involved with their own families and many had various social activities which regularly brought them into contact with friends and acquaintances. By implication they were individuals who would be regarded as having 'high social loss' (Glaser,1966). Since their initial diagnosis the majority of the study group lived (at least initially) at home in regular contact with their own families and were still, in general, capable of participating in some normal social activities. As such these individuals served as a reminder of human mortality in a way which is not usual with those who find themselves dying alone and isolated. This may account for the difficulties they experienced, as I shall now discuss.

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As respondents spoke about others avoiding them, it is perhaps useful to consider their own explanations of why this was the case:

> I don't think people want to hear about it, they don't want to hear about the gloomy side of life. (Rachel)

> Generally, I don't feel that people are interested to be quite honest. When I first got ill your friends sort of sorted themselves out. I don't want to put myself in the situation again where someone feels awkward talking to me. (Ann)

Walter (1994) suggests that such avoidance is simply attributable to the fact that in contemporary society people do not know neighbours as well as they did historically and, therefore, when faced with deaths in their locality really have very little to say, except to express a few words of sympathy. However, respondents did not only talk about having difficulties with acquaintances, but also close friends and family. Their experiences may be partly attributable to the fact that in modern society there appears to be no commonly available coherent language for discussing death which results in the conversational unease and embarrassment they describe (Walter,1991). This argument implies that it is not that others do not want to see or talk to those who are in some way directly affected by death, but that they simply do not know what to say to express their feelings. Thus social inability and the embarrassment this causes means, as I have shown, that individuals are often left at best having to deal with 'strained' situations or at worst feeling isolated.

As noted earlier the body has become an important focal feature of an individual's self-identity. In today's 'consumer culture' there is an emphasis on healthy, youthful, trim, sexually active bodies (Featherstone,1982). Consequently people generally invest increasing time and effort into sustaining and improving their bodies (Bauman,1992). It is our responsibility to stay fit and healthy, indeed it may often appear that if one behaves in a responsible and 'correct' way perhaps death should, logically, be at least deterred, if not even avoided. Such a view is further enhanced if one considers that death is increasingly reduced to individual causes, and implicitly individual failings (Bauman,1992). However, the dying, particularly the 'blameless' (as many of my respondents are likely to be perceived), show this is not the case and therefore represent a threat to

those values and beliefs we are encouraged to hold dear. The dying symbolise the fallibility of the human body, they make death real. Death is, as Bauman notes:

> ....the ultimate failure of rationality: Human inability to reconcile the transcending power of *time-binding* mind and the transience of its *time-bound* body. (1992,1 - original emphasis)

Given this it is not surprising that those who serve to remind the living of their own inevitable deaths are avoided.

> In the West there is a tendency for modern individuals to be left increasingly alone with their bodies in the face of death. Our bodies come simultaneously to assume great importance, as carriers of life, and to appear acutely fragile and insignificant as mortal entities which will eventually die. (Shilling,1993,19)

Mellor and Shilling (1993) assert that individuals who are themselves unable to face the inevitability of their own demise find their self-identities threatened when faced with dying and death in others. For example, the bereaved frequently comment on the fact they feel isolated and ignored by others (e.g. Littlewood,1992,1994; Cline,1995; Wright & Coyle,1996). Such insecurity can be partly seen to be responsible for the "....fundamental shift in the corporeal boundaries, symbolic and actual, associated with the dead and living" (Shilling,1993,188). That is both dying and death are sequestrated away from the public gaze, so that only those who choose to need confront the reality of 'failing' and 'failed' bodies. Such behaviour can be seen as a 'survival strategy' (Bauman,1992). Those of us who believe ourselves to be fit and healthy, having the capacity to live many more years, do not want to trouble ourselves with human mortality. However, death becomes problematic when it affects our contemporaries, our sexual partners, because we are reminded of the fact that it also lurks within our own seemingly healthy bodies (Mellor & Shilling,1993). This may be relevant to respondents' feelings of exclusion, their dying status may have presented difficulties to their friends and family because of their ages. This would perhaps seem to suggest that it is only the young who find the presence of death in others disturbing, however, more elderly people, engaged in planning their long-term futures, may be equally affected by any reminder of the inevitability of death.

Given both the increased emphasis on a healthy body, coupled with an orientation to planning one's future, it is unsurprising that:

> A diagnosis of cancer threatens our carefully conformal identity, estranging it from normal reality. Victims of cancer frequently express feelings of isolation and alienation because the label confers discredit. These feelings are compounded by the felt perception of avoidance, lack of understanding and prejudice from social 'normals'. (Colyer,1996,499)

Perhaps the most appropriate way to describe the position of the dying is to employ Simmel's concept of the 'stranger'. Simmel defines the 'stranger' as ones who is both part of a group and yet outside of it. (Wolff,1950). This would seem to be pertinent to respondents' experiences, at one and the same time they remain part of the same groups and sub-groups they always have been and yet they are now separate. Their new experience as someone who has cancer and is dying places them outside the experiences of the wider group. Such a view is apparent from Rachel's and Liz's statements:

> I felt, you know, it's Christmas, but it didn't really mean much, because I couldn't get involved. I felt an outsider. I couldn't even sit at the meal table and eat my meal...I couldn't even have a drink. (Rachel)

> It's a funny way to feel, you feel of the world, and yet not of the world... I look outside when the sun's shining and think isn't it beautiful, but I feel like I'm shut away from it all and it's not for me anymore. (Liz)

Respondents were made to feel 'outsiders' by the most unintended of actions by others. An apparent act of kindness or consideration by others could merely serve to reinforce the notion that the individual was no longer the same. Katie said of her daughter's wedding[3]:

> They do things out of the goodness of their hearts, like, "We don't want you to get tired, go for a rest." "No, I don't want you helping me to get ready for the wedding mum, we want you to rest and sit there." But it's like trying to be a dummy all the time, sitting on the outside, watching everyone get on and do things.

Such feelings of 'otherness' are also experienced by other groups, who like my respondents could be viewed as having a disrupted lifecourse and also being stigmatised. For example the 'infertile' and/or 'involuntary childless' can be said to have a disrupted lifecourse in a pro-natalist society. Letherby (1997) found that many of her respondents felt that others perceived their childlessness as problematic, it was a stigma, and as such they at times felt excluded or marginalised by family

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[3] Also see Sarah's quote p172 for another example of this.

and friends, they became 'outsiders'. Similarly Riches and Dawson note that the bereaved parents they interviewed referred to themselves as 'a community of insiders', one respondent said, "This is a very exclusive *club*, I hope to God you never join it" (1996,145).

Walter (1994) argues that in modern society, given increased secularisation and a decrease in rituals, dying is a process which is often learnt and mutually constructed. Even if one does die in one's 'own way', he asserts, this is still constructed with other people. If one accepts this view it is possible to see that respondents may have 'learnt' what would be considered 'appropriate' or tolerated from them by considering their own perceptions about cancer before their diagnosis, but more importantly reacting to the beliefs and actions of others. They would be aware that dying is not a valued role, and that they were now in some way different to the majority of people around them, 'outsiders'. They would learn that if they wished to be treated in the same way as others they need to make a conscious effort to prevent their dying cancer status from taking over, and therefore they needed to engage to a lesser or greater extent with 'stigma management' (Goffman,1990b). Such 'management' requires, as I shall discuss in the next chapter, a great deal of time and effort, and further it takes a variety of forms depending upon the situation in which individuals find themselves.

Chapter 7

Living with Cancer: Living with Dying

In this final data chapter I consider the ways in which respondents managed their lives in order to maintain and reaffirm existing self-identities. In addition I discuss how they also negotiated new roles within their own lives and the lives of others. Control has been a recurrent theme throughout this thesis, and in this chapter it is an important factor again. As I discussed in the last chapter, a diagnosis of cancer and a subsequent terminal prognosis had a considerable impact both on respondents' relationships with others, and on their own self-identities. Such changes required skill and effort in their management in order to reaffirm other, more valued, identities or to establish new ones.

> Cancer imposes a level of change and disruption that cannot be easily assimilated. Individuals are forced to reorganise central aspects of their personal worlds and that involves changes in their perceptions of meaning, both with regard to their identity and the social contexts in which they find themselves. (Fife,1994,315)

In this chapter I consider the ways in which respondents reorganised their lives as a result of their cancer and dying status. Adjustment and reorganisation are important and continuous processes given that dying in the case of terminal cancer often takes place gradually.

> The process of dying takes place in many ways and on different levels of experience. We die to many things before we die of a disease. Small, partial deaths gradually become more confluent, so that we may cease to be as an autonomous person long before literal terminus takes place. (Weisman,1972,57)

Individuals are rarely active and participating in full social interaction one day, and dead the next. It is this degenerative and prolonged process which necessitates the reorganisation of individuals' lives and the renegotiation of their self-identities, if they are to continue to actively participate in normal everyday social interaction with others.

As I discussed in the last chapter having a terminal illness often changes social relationships profoundly. Such changes affect an individual's self-identity, because we define ourselves, as

well as others, through our relationships (Charmaz,1997). Given the changes which appeared to occur in respondents' relationships at this time, in this section I consider the ways in which individuals attempted to manage their self-identities in order to reaffirm their social worth. I am particularly concerned to consider the role of emotional work in this process. It is well documented that caring for the dying presents health professionals, particularly nurses, with dilemmas and difficulties which require they use both physical and emotional caring skills (Ramirez *et al*,1998; Smith,1992; Kiger,1994; O'Brien,1994). James argues that:

> The time of impending death is a particularly obvious example of how the form in which emotions are expressed is subject to social expectations and negotiation....Modern Death is more likely to take place in an institution, with health care professionals doing the 'work' formerly carried out by the family and shaping the ways in which predictable emotions associated with death are expressed or repressed. (1989,19)

However, it is not only the carers of the dying who are involved with emotional work, nor is such work necessarily confined to a health care institution. While it may be the case that health professionals are involved with 'emotional labour' when a terminally ill person is admitted to a hospital or hospice, it is important to note that the majority of dying takes place within the home (Field,1996). Thus much of the emotional work at this time will also take place within the home. While health professionals based in the community, as well as friends and family, may become involved with some emotional work within the private sphere, some of the burden of this work will fall on individuals themselves (Exley, in press). The majority of respondents were still living at home when interviewed, and frequently either spoke openly about, or alluded to the strategies, that is the emotional work, they used to 'manage' their interactions with others. Given that similar work undertaken by relatives and close friends after death, for example 'grief work', is accepted, it is important therefore to acknowledge the emotional work undertaken by individuals themselves prior to death (Martens & Davies,1990).

Living with cancer and dying

I begin my discussion looking at respondents' experiences of living with a terminal prognosis by firstly considering (in brief) their emotional responses to their diagnosis, I then move on to focus on the strategies they used to manage their normal everyday lives. When considering respondents' comments it is important to note again that for many their initial diagnosis of cancer had occurred some time ago, and they were looking back with hindsight. It may be argued therefore that their accounts could be viewed to some extent as 'impression management' (Goffman,1990b). For example, all respondents to a lesser or greater extent tended to portray themselves and their reaction to their diagnosis, treatment and the future in a 'positive' light. Such presentations serve to negate, or detract attention away from, the view that sees cancer patients as 'helpless victims'.

A commonly cited initial reaction to the diagnosis of cancer was "Why me?",

> .....yes, I do feel a bit angry now. I suppose everybody has that. Now I feel, you know, sod it, I've had the bloody thing for 6 years, you know, three times, you know, why couldn't I have had it and got better? (Anna)

When discussing the reaction of 'why me', respondents emphasised that although they were angry that had cancer, they did not wish any ill health on others. For example Rebecca said:

> I think why me? Not that I would want to wish it on anybody else. Not so much why me, but there are things I want to do and it's frustrating, I want to have a crack at these things.

The question "Why me?" clearly implies a sense of being blameless. As I discussed in Chapter 4 it would seem that an important feature of living with cancer for some individuals is the desire to absolve oneself of any responsibility for the genesis of the disease. For example, a number of respondents alluded to the fact that they felt that there was nothing they could have done to prevent their cancer because it was attributable to 'fate', or something out of their control, which meant that they had cancer.[1]

> Just my number isn't it? Just in my book of life. It says, "Right you're going to get cancer." That's it there's nothing that I can do about it. Nothing anyone can do about it. When your number's up, your number's up isn't it? (Sarah)

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[1] Also see Katie's quote, Chapter 6 p159, for further illustration of this point.

It's like your number's in that little book and whatever happens, it happens, doesn't it? (Gill)

Given the apparently arbitrary nature of the disease respondents commented on how they now needed to 'make the best of the situation' and continue living their lives in as normal a way as possible. Gail said:

I've had a couple of tears, but mostly I take it in my stride. I mean I've had a good time, it's life isn't it? You can't run away from it, nothing you can do, I think you just have to get on and see it through as best as you can.

Another strategy used was to console oneself by reflecting on the past. Liz commented on the fact that she felt that she had had a 'good' life prior to her diagnosis which appeared to enable her to cope with her current situation. She said:

I think I've done quite a lot of the things I've wanted to do. Mind, when you get news like this you always think I wish I'd done so-and so, but they're just wishes, you probably wouldn't've done it if you'd had the opportunity anyway. But I've done the things I wanted, quite a lot of things I wanted to do. And I've been lucky I've had a very happy life with my husband and family.

Just as some respondents said there was nothing they could have done to prevent their cancer developing some continued to adopt this view when living with their terminal prognosis. For example Roger reflected on the fact that his attitude throughout his illness had been one of addressing those things he could influence, and trying to forget those he could do nothing about.

When I found out I'd got cancer, and secondly when I found out it was terminal, I felt the same on both occasions, that, OK, if I've got it there's nothing I can do about it. So let's concern ourselves with now and what's going to happen.

Trying to remain hopeful and optimistic about the future was another strategy used by respondents. Again this is not surprising given, as already noted, much of their care was conducted in environments where a 'positive' outlook is actively encouraged. Ann said:

I don't know how long I'm gonna last, you know, just don't know, just have to live each day as you go. There's no reason why I should pop off tomorrow now really, realistically.

Similarly Gaynor also commented on how important she felt it was to remain hopeful. Such an outlook was not only designed to help her family, but Gaynor also alluded to the fact that she felt that positive thinking may in fact also have physical effects:

I mean the thing is as well, what can they tell me? They gave me these tablets, I mean they could say one thing and it's not true, it's no use looking on the black side all the time is it? Cos, I don't look on the black side, sitting here talking to you really, I feel I don't feel too bad actually.........I do believe as well that some of the time it is mind over matter, because some people if you say to them, "You're going to get that," they get it, don't they? I mean you can talk yourself into feeling a bit urgh. I can talk myself into feeling great, I mean I know when I don't feel well but I can say, "Come on, Gaynor, get ya sen picked up."

Given that trying to be optimistic is often regarded as 'appropriate' behaviour by health professionals, it is not surprising that respondents appeared to want to illustrate how they were being as 'positive' as possible, 'fighting' their illness and not allowing it to 'win'. Both Rebecca's and Katie's words illustrate this point:

There's very few days when I actually feel that I've given in to it. (Rebecca)

All I can tell you is you've got to be positive. You've not just got to sit there and think, "I've got cancer." You've got to be positive and get on with it and forget it and take it one day at a time, and then at the end of the day think, "I've gone another day, this is wonderful!" And do things you want to do. Take time out for yourself, it's not a rehearsal, this is it. (Katie)

Presenting oneself in terms of 'not giving in' and 'fighting' is particularly pertinent to my later discussion of the 'heroic' death (Seale,1995a).

One common way respondents spoke of managing their lives was through taking things 'day by day'. Karen said:

You just live for each day and carry on and hopefully hope.

Giddens (1991) suggests that such behaviour may be seen as a means of 'bracketing out death', that is denying the reality and inevitability of death by concentrating on current events and concerns. Young and Cullen (1996) note that some of their respondents, although still to some extent concerned about what would happen tomorrow, also became more preoccupied with what was happening to them at the present moment. In addition to these points, thinking and acting on increasingly a predominantly day-to-day basis may be partly attributable to respondents increasingly variable physical state. As Liz put it:

I feel it's under control at the moment...you've really got to go day by day, because most days you don't know what you're going to feel until you get up and start moving.

Concentrating on the present rather than the future could also be seen as being 'appropriate' given the apparent need to use one's remaining time 'wisely'. Katie said:

> I get a bit down, but not very often, I haven't got time for it. I don't want to waste it. I forget about yesterday because you can't do anything about that. Don't look forward to tomorrow because you're wasting today. I don't know how else to cope with it.

Given the future oriented nature of contemporary society, it is not surprising to note that attempting to live one's life on a purely day-to-day basis could be very demanding, as Edna commented:

> The hardest thing for me is to live life on a day to day basis, because I've always been one of those persons, I want to know what's going to happen.

As respondents often spoke about taking things a day at a time it seems incongruous then to say that another way of managing their lives, and maintaining hope, was making and fulfilling short and longer-term goals. Although the nature of planning for the future may change it is important to note that it does still take place.

> Cancer greatly reduces freedom. What remains is all the more precious....Our patients had to shift for themselves and maintain some control to prevent themselves from being overcome by their lack of future. They wanted to do as much for themselves, and for others, as they possibly could, and they wanted to be given the chance to construct their own futures in a manner which was peculiarly their own. (Young & Cullen,1996.49)

However, planning may also have another important function for the dying in our future oriented culture. Such behaviour could be viewed in terms of 'deviance disavowal', that is the refusal of an individual viewed as deviant to accept such a label. Alternatively, it could argued that individuals engage were effectively engaging in 'role distancing' (Goffman,1978). They wanted to reassert their self-identities, because having goals and planning is part of normal everyday life, by engaging in this behaviour the dying are able to detract away from this status and reassert their 'normality'.

> Serious illness frequently threatens assumptions one makes about life and one's place in the world; therefore a significant task in coping with illness is to continue reaching towards goals that were established prior to the crisis, or at the very least re-defining

the event and its meaning so it fits realistically within the context of one's life given changes imposed by the illness. (Fife,1994,314)

Both Anna's and Sarah's plans involved friends and/or family, they said:

We've got a do to go to in December, it's a friend's Bar Mitzvah.....it's something to aim for even if it's only for an hour. I've got to try and do some of it. (Anna)

1st June I'm going to Devon for a week, then we're back for two weeks and I've got Alex's [son] birthday party which is on the 28th June. Then on 1st July I'm going to Italy with a friend, so it's a bit busy. (Sarah)

Both Rachel and Katie wanted to attend their daughters' weddings. Achieving this goal would not only mean participating in 'normal' celebratory events with others, but, more importantly, it would also give them a new identity - 'the bride's mother' - which they both valued and looked forward to. Katie said:

My daughter told us last week, she's been living with her fiancé for quite a few years and they'd like to get married this year in August. So all of a sudden my goal is keeping well, keeping going, but I know I'm getting worse

In her next interview after her daughter's wedding Katie told me how her hopes and plans for the future had now changed.

I've got to kept thinking that things'll be alright, I've done that, now what do I want to do? Gina's got married, I've been to Sheringham, I'd like to see my brother and perhaps go home to my roots....I've got to have different goals. So I say it's Gina's birthday to look forward to, and then if my brother comes in The Fall, and it's our wedding anniversary in October, birthday in November, then it's Christmas. So I've got little goals to work for.

Goals were not necessarily have the grand propositions discussed above, at times they were more modest. This is perhaps partly attributable to the fact that

The cancer patient must ultimately decide how the events of illness fit in among the events of her life. This inevitably entails revision of future plans. (Mathieson & Stam,1995,299)

Although seemingly 'less significant', the goals which individuals made were clearly of considerable importance to them. This was certainly the case for Gail:

Right from the beginning I've always set myself goals...I used to say, "I'm going to wash those cups and saucers today," and even if it took me all day to wash half a dozen cups and saucers then that would be what I aimed to do. And then gradually as I got better you increase the goal, and I think that's the way to do it. You've got to have something realistic, you know.

Young and Cullen note that the setting of goals were also important to their respondents, because:

> ....they could still make a plan but one which took account of their circumstances and set goals which should be attainable.....Fixing their mind, and their resolve, on the target meant there was somewhere for the procession of ordinary days to proceed to. To stay alive until then could be seen as an achievement. (1996,59)

Thus it can be seen that planning meant that respondents were still engaged in the same social activities as those around them. With reference to my discussion in the last chapter, they were still at least partially occupying the more valued position of 'insider' rather than 'outsider'.

The 'Advantages' of Dying of Cancer

Although dying in general, and more specifically dying of cancer, is likely to be perceived as a largely negative experience, research has shown that actually individuals do identify some positive aspects (Fife,1994; Taylor,1995). For example, cancer gives people 'permission' to do things they would not normally do, or have stopped doing. In my own research, on a light-hearted note, Liz commented on how she felt her illness allowed her to indulge her love of sweet things:

> It's not nice to lose weight, but what's so funny is that I go to bed with a bag of crisps, big bag of chocolate and sweets and pig out. I'm pushing sweets down me like there's no tomorrow. "Let me get to bed so I can get to my chocolate!"...I love peppermint things, and of course peppermint's good for your digestion, isn't it? So, I have a creme de menthe before going to bed.

Similarly Roger resumed smoking cigars which he had given up some years ago. Respondents often pointed out that although initially shocked and scared by their diagnosis, they now felt that having cancer had some positive effects on their lives. Some individuals also changed their behaviour for what they perceived to be for the better as a result. Liz felt that her cancer was attributable to stress, subsequently since her diagnosis she felt she had reduced the amount of stress in her life, which she regarded as being a positive outcome of the disease. She said:

> I am learning that I can't take everyone's worries on. I probably don't so much now. I'm not really quite as bad a worrier as I was before, apart from myself, obviously I worry about myself. If you like I've learnt my lesson because if I think, "Oh I blame it on stress," I've just not got to worry so much about everyone else.

Margaret also felt that she too had changed as a result of her diagnosis, she said:

I think I'm more tolerant than I used to be, and I've certainly got more patience, I don't let things worry me too much. I think well if you can't do it, you can't do it. I try and if I can't do it I accept it. I don't like it, but I do know my limitations.

Edna and Ann both felt that they had 'learnt', which they viewed as being positive, from the experience:

That's one of the things I've learnt, you learn, you don't realise how strong you are and when you go through day to day life and then you're told that you've got cancer, a terminal illness, and all of a sudden you're faced, you've got time to sort things out and that's what I've done sort myself out and get rid of all those hang-ups from the past. .....I've learnt how to be patient because I wasn't patient, never been patient. I know I've learnt so much about me over the last three years. (Edna)

We've learnt from the disease, and how valuable life is as well. You know you're glad you're alive really, however horrible things are in life and things happen outside which you don't like, or perhaps you haven't got enough money for something, it doesn't matter really, you've just got a better outlook on life. (Ann)

Although a diagnosis of cancer does severely disrupt an individual's lifecourse, it would seem from respondents' accounts that there were benefits or gains from the experience. Anna felt there were still some 'good times', and Gail felt that her diagnosis made her appreciate everyday things more than she had in the past:

But we've had plenty of time for cuddles and things, and it's been good, it's been good in some ways. (Anna)

I've been out this morning, sat in the garden, had my lunch out there, so it was really nice. Feel a bit of breeze and sun on your face, it makes you feel so much different. Things you take for granted normally you're so aware of now. (Gail)

One 'advantage' frequently cited was that dying of cancer (compared to other illnesses) allowed people time to plan or make amends. With reference to this Judy commented:

I feel quite privileged that I have the opportunity to plan what's going to happen. To plan who's going to have what, some people don't have that....I've got the chance to say goodbye, to make amends with people and I feel very privileged to be able to do that.

Both Edna and Gail compared dying of cancer positively with the experience of dying suddenly, particularly of a heart attack:

One thing about having cancer you're given time. Where as with people who have a heart attack, or are knocked over, there's a lot of things left unsettled, where as when you've got cancer you've got time to sort out your priorities and do all those thing, say things that you've always meant to say but you didn't have the time. That's one

of the, well no-one can say that having cancer's a bonus, it shouldn't be wasted this time that you've been given. (Edna)

It's been nice because you can use the time well, because there are things you want to say to people or perhaps you wanna do, and it gives you that time....We've talked about it all the way through, I mean we've even been sort of organising what sort of funeral, so that everybody knows each other's wishes and you plan it together, I think it makes it a bit easier...If I'd suddenly died of a heart-attack they wouldn't have a clue. (Gail)

Another 'advantage' of the diagnosis was that their cancer actually gave some individuals new opportunities, they developed new roles which gave them satisfaction and fulfilment.

Many survivors talked of offering help and support to others....Many more described seeking out newly diagnosed women who might need information or advice. It appears...that friendship networks and support may be important not only because they bring something, particularly concrete help and information, to the women with breast cancer but also because they indicate her active involvement in and initiation of relationships. (Waxler-Morrison et al,1991,181)

Although Katie did not actually initiate contact with other patients herself, it is possible to see from her experience how the belief that she was helping others enhanced her feelings of self-worth. She said:

I felt good because I could help people because after having a couple of treatments...the nurses would tend to sit [new people] next to me and say, "Oh you can have a chat with them Katie." So that made me feel good because I could help other people, and tell them how it's affected me.

Acknowledging positive aspects to living with cancer can be viewed within the broader context of attempting to maintain a sense of control over one's life. Taylor (1983) refers to this process as 'gaining a sense of mastery':

A sudden threatening event like cancer can easily undermine one's sense of control over one's body and one's life generally....A sense of mastery then can be achieved by believing that one can control the cancer by taking active steps that are perceived as directly controlling the cancer or by assuming control over related aspects of one's cancer, such as treatment. (1983,1163-4)

Changing behaviours for what they believed to be the better is one way in which individuals 'gained a sense of mastery' over their cancer. Forsyth et al suggest that :

Faced with a disease that promises progressive damage and intrusion.... patients fight to maintain hope and a feeling that they are winning over encroaching disease. This involves adopting specific attitudes with convince patients that they are not helpless victims of a progressive illness. (1984,183)

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They refer to this process as 'vying for a winning position', seeking to reinforce or adapt valued identities even negotiating and establishing new roles other than that of the terminally ill cancer patient. Following on from these notions of 'gaining a sense of mastery ' and 'vying for a winning position', it is interesting to note that respondents also spoke about how they sometimes compared their own physical condition, experiences and reactions to those of others, generally those perceived as being 'worse off'. Wills (1981) refers to this process as 'downward comparison', whereby individuals compare themselves to others less fortunate than themselves, and in doing so increase their own subjective feeling of well-being. Similarly, Forsyth *et al* discuss a process of 'comparative optimizing', which they describe thus:

> This was perceived when patients described their situation in terms of the other patients greater pain, inflicted at an earlier age, or having a disease with harsher ramifications.(1984,185)

Such comparison prevented or limited the extent to which respondents felt that they had been 'treated' unfairly, or serve to remind them 'how lucky they were really'. After Sarah's final interview I made the following notes:

> After I switched the tape off after Sarah's interview today [third interview] she said that she had always thought that cancer was the worst thing you could get and she talked about the fact that there's always hope with cancer because they're always coming up with new treatments. Then she talked about a man at the DCC who had got Motor Neurone Disease and that it wasn't until she met him and saw what he was going through that she realised that really cancer isn't the worse thing you can get. She said she thinks she's lucky because she's got the hope that something might come up because they're always bringing out new treatments. (Fieldnotes 15.4.1996)

The cliché 'there's always somebody else worse off....' would seem to be appropriate in describing the attitude of respondents when they spoke about the experiences of other people. For example Liz felt that it must be worse for younger women:

> I don't know how young people, a young woman would cope, who's got a family and told something like this, it must be very difficult...I mean I've seen my family grow up.

In contrast Anna felt that it must be worse to be older and alone:

> It must be very hard for them [hospice staff] when it's little old ladies all on their own, with no family. I'm very lucky like that I have got a family, and good friends, so I'm cushioned if you like, it makes it easier.

Just as children who were undergoing chemotherapy and radiotherapy were said to 'help' respondents deal with their own treatments, both Katie and Gail also referred to the fact that in comparison with such children they felt they were to some extent 'privileged':

> I mean OK I'm 50 I've had a good life that's the way I look at it. What about these kids? They've had no life, that's tragic....I used to go up on the ward and you know, my God, "If they can do it, so can I. Don't you dare start whinging Katie!" It makes you feel very humble these children. (Katie)

> I feel alright about it, I don't feel bitter, I don't think why me? The thing that's always got me through is seeing children that have it, I think it's such a shame and that's one of the things that spurted me on in the beginning because I used to think, "If children can go through this and beat it, so can I! (Gail)

Comparing themselves to others was an important process because:

> People worse off than you can also give a strange sense of comfort. You have been so sorry for yourself, but now there are all these others. (Young & Cullen,1996,45)

However, comparing themselves to others did not merely serve to remind individuals of 'how lucky they were', as was sometimes the case above, but was also used as a means of 'reassurance'. For example Sarah used the perceived reactions of others as a 'yardstick' against which she could measure her own responses. Having read a number of book and leaflets and watched numerous television programmes about others' experiences of living with cancer, she came to the conclusion that she could not be in such a bad situation as them because she did not feel the same way as them. She said:

> So, I thought things are going along, and I'm just chuffing along with them thinking you know everything's fine, so it didn't really scare, me as much as I thought when you hear it on television, you hear people talking about it and how they reacted. I thought I'm not reacting like them so I must be alright kind of thing.

The dying hero?

In my discussion thus far the ability to at least partially control one's own life and surroundings has been a recurrent theme. As noted in Chapter 4 individuals felt more comfortable in medical consultations when they felt they were to some extent 'in control' of the encounter, however, such feelings were also important in respondents' personal lives. Even when their physical capabilities were limited, and decreasing by the day, ensuring that they at least maintained some of the

'standards' they had before their diagnosis was important in terms of maintaining both self-esteem and self-identity. During the inevitable process of physical deterioration being optimistic and hopeful was one way in which individuals were able to maintain some sense of control in their lives. Again militaristic metaphors were recurrent throughout individuals' accounts; speaking about oneself in terms of 'fighting' appear to be an important part of the cancer patient's role:

> Just doing the housework I feel like I'm fighting, instead of just laying there. I think you fight it more mentally when you're ill, when you're feeling down and having treatment. (Sarah)

> I fought it with everything I've got in the beginning, I think I fought it all the way, but as time's gone on I've know that I'm losing, but I don't feel that I'm giving in to it, and I still feel that I'm giving it a good run for it's money, I won't give up easily. (Gail)

Such descriptions are not surprising when one considers, as noted earlier, that 'fighting' the cancer appears to be encouraged and expected by both health professionals and lay people alike. It is interesting to note that although individuals referred to the fact that they were 'losing' their 'battle', to the extent that they knew they were dying and there was nothing that could be done to change this fact, they were keen to point out they were still in control in other ways. For example, Katie spoke about how it was important for her to 'go on her own terms':

> I'm 50 I've got two kids who've turned out to be two nice human beings and I've been happily married for 29 years and there's nothing that I haven't done, so that's how I feel, and if I'm going to go I'd rather go in my own way digging the garden in two weeks time than go in hospital with a tube up trying to adjust things to extend my life....I'd rather go on my own terms than the cancer telling me when to go.

Similarly, Anna was keen to dismiss any image of herself as a passive victim, she achieved this by taking active steps to organise her family's life as much as possible in order to help them cope with her loss. She was particularly concerned to finish plans she had made some time ago, but had never got round to actually doing. She said:

> I've got a carpet man coming in to lay some new carpet in both the boys' bedrooms because they're so tatty. I'm sure they will move, but having said that it might take a couple of years before they want to move, or whatever. You've got to keep up with it, and they need new carpets, so we're having new carpets this afternoon.

To perceive oneself as 'fighting' and to be viewed as a 'fighter' by others appears to be an important identity for the cancer patient. To present an image of someone who is not 'giving in' is very important, there is a need to justify any decisions which could be perceived as such. Throughout my interviews respondents spoke about feeling angry at times, but also pointed out that this was only occasionally, therefore resisting any potential label of being 'irrational' or 'hysterical' or 'unable to cope'. Similarly, "raging against the dying of the light" is another image which does not concur with the expectations many people have of individuals with cancer, who should be 'stoical' and 'brave'; those who 'fall apart' are difficult to deal with, and present problems in social interaction.

Clearly a diagnosis of cancer has a significant impact on individuals' lives.

> Faced with a disease that promises progressive damage and intrusion....patients fight to maintain hope and a feeling that they are winning over encroaching disease. This involves adopting specific attitudes which convince patients that they are not helpless victims of a progressive illness. (Forsyth *et al*,1984,183)

Seale (1995a) suggests that dying can be incorporated into the reflexive formation of self-identity, through what he refers to as 'heroic death'. In 'heroic death' awareness and acceptance are the ultimate goal, even if at times the emotions individuals experience are difficult to bear, the 'struggle' through them is an important factor in the construction of the heroic death. Seale (1995a) asserts that an awareness of one's own dying is an "affirmation of the project of self in the face of the ultimate threat of selfhood" (606); difficult though this may be, he asserts it is particularly necessary in an increasingly secularised society where "religion and other traditional narratives no longer sustain the individual" (606). As mentioned earlier the 'heroics' demonstrated in this dying are not traditional masculine heroics:

> The everyday world is one which the hero departs from, leaving behind the sphere of care and its maintenance (women, children and the old), only to return to its acclaim should his task be completed successfully. A basic contrast then, is that the heroic life is the sphere of danger, violence and the courting of risk whereas everyday life is the sphere of women, reproduction and care. The heroic life is one in which the hero seeks to prove himself by displaying courage. (Featherstone,1992,165)

The hero within this context shows courage through demonstrating physical bravery, although it could be argued that the 'courage' demonstrated by the dying may involve having to overcome physical limitations of their disease, Seale suggests that the heroics demonstrated by the dying are essentially feminine in characteristic.

> The inner adventures of self exploration, and the depiction of emotional work as sacrificial, contribute to a late modern heroic script which has been powerfully underwritten by some feminist ideology relayed via both professionals and the media. (Seale,1995a,599)

I would agree that the 'heroic' behaviour demonstrated by my respondents was indeed concerned with 'everyday life' and did involve emotional work, and, as discussed elsewhere, certain behaviour - for example, fighting - is actively as well as implicitly encouraged by health professionals. However, I would suggest it is too simplistic to present such emotional work merely in terms of being sacrificial, for the benefit of others. The emotional work of the dying serves a number of functions. It was indeed used to make others feel more comfortable around the dying person, however, more fundamentally I would suggest it was a means through which respondents re-negotiated and affirmed their self-identities.

The emotional work of the dying

It could be argued that the very fact respondents were attempting to continue to live their as fully as possible demonstrates the emotional work they were engaged with; actually coping should itself be regarded as work (Martens & Davies,1990). The emotional work of the dying may also be seen as part of the process of refusing to accept the stigmatised labels applied by others; that is another form of 'deviance disavowal'. Although Goffman does not use the term 'emotional work' he does note the importance of the effort required of stigmatised individuals to make interactions less stressful.

> When the stigmatized 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. (1990b,141)

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."(1990b,125), by reducing any tension and thus enabling normal interaction to continue; they are engaged in 'impression management'. Such behaviour is common in any situation where the disclosure of certain information could be potentially stigmatising:

> ...the person with the ileostomy has to become highly skilled in the arts both of impression management and of maintaining a viable sense of self which might be undermined by unwanted public disclosure. (Kelly,1992,409)

The fact that this discussion of emotional work is primarily concerned with the private sphere (although this is not to say that it did not take place in the public arena too) can partly be understood by the fact, in the 'civilizing process' the social regulation and management of emotions is learnt, and concentrated within the nuclear family in the home environment (Elias,1994). Equally it is not surprising that there is a discussion of emotional work within a study where the majority of respondents were women:

> Women's assigned role in recognizing and meeting the emotional needs of household members therefore calls for considerable 'emotion work' - a sort of 'emotional housework' or 'invisible domestic labour. (Duncombe & Marsden,1993,234)

The fact that the women in my study were involved in emotional work at this time is perhaps therefore not surprising, and may be reflective of the other roles and responsibilities they had undertaken throughout their lives.

A recurrent theme from the interview data was respondents' desire to try to ensure that life remained as normal as possible, in the hope that this would allow family and friends to feel more at ease. However, individuals appeared to want to detract attention away from their dying status not only to maintain an air of 'normality' but also, and perhaps more importantly, to reaffirm their other more valued self-identities, such as those of mother, sister, or friend. This sometimes meant, for example, trying to do the chores they had always done (even those which were loathed) which were part of their particular role.

> For patients, it was important to maintain regular family life, both for their own sake and the sake of loved ones. (Marten & Davies,1990,66)

In order to facilitate the feeling of 'normality' some respondents tried to hide their own feelings from those around them as much as possible. As Anna put it:

> I might be suffering mentally but they can't see it outwardly, so it makes it easier.

Gaynor and Karen both commented on their own role within the family, and felt that to show their own feeling and to break down would be damaging to her family:

> ...they're the sort of family, as long as I'm strong they're strong.... I think if I went into hysterics I'd drag them along with me. (Gaynor)

> There's times when I feel I just want to burst into tears but....I don't want to upset the rest of them because they support me as much as they can. And I feel that if I'm going to get down in the dumps and feel low and crying all the while it's not going to help me and it's not going to help the family. (Karen)

Similarly Judy said that in the past she had felt:

> All the time I was still trying to be the stiff upper mum, I had to cope with my family, cope with my husband, cope with my children, cope with everyone who had got problems.

It would seem that such emotional work meant that individuals were able to engage in what may be seen as 'surface acting' (Hochschild,1983), that is although not immediately apparent to others, the individual's true feelings were not completely hidden (compared to 'deep acting' where the outward image being presented overrides the individuals' own feelings totally). 'Surface acting' was fundamental if respondents were to successfully manage their social interactions in this way, because they felt that to reveal their true feelings and concerns would be damaging to their relationships with their friends and family, and thus disrupt the 'normal' atmosphere they were trying to create.

Emotional work is not merely controlling emotions. When respondents believed that others avoided them, or were uneasy in their presence, their emotional work was designed to make other people feel more comfortable. Nurses often labour emotionally to establish a rapport between themselves and the patient in order to reduce anxiety (O'Briens,1994; Phillips,1996); and it is

interesting to note that similar strategies are also employed by individuals themselves. For example, Gail said she wanted to make her friends feel as at ease as possible, she tended to move the conversation away from any discussion of her illness, and concentrate upon the things she had always been interested in:

> I think you find that when you've got someone who's terminally ill silly little things, like, they don't like to send a get well card, because they know you're not going to get well. It's things like that isn't it, and I just, I would hate for anyone to feel uncomfortable about it, so I always try to turn it. I mean I say if I'm having a good day or whatever, but I get off the conversation and talk about things in general, which is what I would like to hear anyway. What's going on out there, what am I missing, what's the gossip, who's going out with who.

Although Roger noted that it was important to talk about things as they arose, both he and Ruth also commented on the need to pick an appropriate moment to hold such discussions:

> ...we made a pact right from the start that we would hide nothing, absolutely nothing, from each other, we don't.

Later:

> There's been times when I've wanted to say to her [wife] when all this is settled down, find yourself a good man... but I think it's a bit too soon. We talk about all sorts of things that could be quite hurtful but we cry a bit or whatever, but we manage to get through, because you know these things have got to be said....[but there are] things that I've got to hold back on because she's not ready. I mean like funeral, what sort of funeral we're going to have....I mean a lot of these things are like a dripping tap, you don't let it blurrgh all come out one evening. We don't have an evening bash when everything comes out, because you can't cope with it, so it comes out in dribs and drabs, and I think it's really the only way you can do it. (Roger)

> You have to pick your time, you have to pick your moment. (Ruth)

Humour played an important role in some respondent's emotional work, this is not surprising given that jokes and humour in general can be used as a means of relieving tension in a difficult situation (Freud,1960; Kahn,1989). Terms relating to 'death' are used in a variety of ways in every day conversation:

> .....we are tickled to 'death', 'dead' pleased, 'dead' certain, 'dead' on time. In each case death is the metaphor through which we suggest that our fear pleasure or punctuality has reached some kind of limit or boundary that cannot be surpassed. (Hockey,1990,39)

Despite this, it is interesting to note that when actually speaking about 'death' we tend to use other metaphors which do not include the word 'death'. For example, of a loved one's deaths people use phrases like "passed on" or "gone to rest"; alternatively the death of someone we do not know well is often referred to in a more humorous way, "kicked the bucket," or "pushing up daisies" (Anderson,1997). I would also suggest that after a period of time such 'joking' references can also be used to refer to the deaths of loved ones, and more importantly as Hockey (1990) notes, to an individual's own death. It has also been documented that professionals, most notably the police, who deal with deaths in the course of their work often use 'black humour'. This may appear extremely crass, or tasteless, to an outsider but is a means by which individuals learn to manage certain kinds of deaths, and thus enables them to complete their task (Mitchell,1996; Young,1995). Cline (1995) in her book often refers to the use of humour in conversations pertaining to death by the dying themselves, their relatives and female funeral directors. She suggests at one point that the use of humour at this time may be a particularly masculine way of dealing with such emotive discussion:

> .....he [Dennis Potter] was facing death with wit but also with hard work on two new plays. I suspect that when he revealed his particular fear of cowardice and his particular reverence for no tears in the fact of death, he spoke for a great many men. (Cline,1995,345)

In my own research I found that women also used humour during the course of their emotional work. Gail's interviews in particular often made me laugh as she recounted the conversations she had with others about her death:

> .....we still laugh and joke, and we're not morbid or anything, but when we need to discuss things we do. I've told mum and dad my wishes, where I want to be buried and which church, what hymn I'd like and which prayer and the rest is what they want. And then of course mum had to ask what I wanted to wear. Which I hadn't given a thought what do you wear to something like this? Because I said to her, "Am I supposed to wear knickers?" You know, got to get it right. I mean who do you ask, "Do you wear knickers to your funeral?" So, we've had a few laughs. I said, "Tell em not to forget my lippy," because I never go anywhere without my lipstick. But as I say you've got to keep it light I think its the only way to handle it, and I think it makes it better for those you leave behind you know.

And later:

> It must be hard for them, and I think that's why I want to try and ease it for them as much as I can. But I think we're doing alright, right for us anyway, might not be for

someone else. ... I mean we're sort of going to go down to the graveyard to have a look at different plots, you know, where I'd like to be. Dad said to me this morning, he said, "It's not a nice thing to do, and it's something you don't want to do." But, I know when we get there we're gonna be saying, "Well, I don't wanna lay there with that tree in front of me." So that's what gets you through it you know.

Humour was also apparent in respondents' accounts when they spoke about 'instructions' they had given to their spouses about what they would regard as 'appropriate' and 'fitting' behaviour after their death. Clearly such a topic is potentially extremely distressing for both parties, therefore, 'keeping it light', as Gail put it, allowed individuals to manage their conversations in a way which was aimed to make both parties feel more comfortable. Spiegel (1990) refers to the use of humour by a woman in his study who gave clear instructions to her husband about how long he should mourn for. Katie said:

> Steve [husband] says, "Yeah, I'll give it a couple of weeks." [to find a new wife] and then we make light of it, When we discuss it it's never serious it's always, "Yeah, give it a couple of weeks." But we talk which I think is quite healthy and good.

Individuals themselves appeared to use humour, or jokes about the subject of their death, to provide a 'gloss' on an otherwise distressing event. This is supported by Langley-Evans and Payne (1997) who argue that light-hearted 'death talk' enables people to distance themselves from their own death, whilst at the same time showing that they are aware of the fact they have a terminal condition. Given this it is clear that humour is an important feature of some people's emotional work. For my respondents it actually served a dual purpose of 'protecting' both respondents themselves as well as significant others, but still enabled conversations about difficult topics to take place.

The desire to 'protect' others in some way was a recurrent theme which emerged from respondents interviews. For example, Ann and Katie said:

> ...maybe I'm trying to protect them because I feel, I'm back to the zone where I think I'm going to die again....and I just feel that if I'm not so close to them it can't hurt them so much, if that makes sense. I think that's why subconsciously why I'm doing it, but yeah, I'm definitely pushing them away. (Ann)

> If I feel bad sometimes Gina'll [daughter] ring up and say, "How are you?" And I'll say, "Oh I'm good, I'm just sitting on the sofa watching TV and that."....But I won't

say, "I'm feeling really ill." They just don't want it day in and day out you know. (Katie)

Waxler-Morrison *et al* (1991) also note that women in their study did not always reveal their feelings to others. However, they point out that an unanticipated outcome of this was that others may not give or offer support which is in fact needed, or alternatively may respond in an inappropriate way because they are not aware of the 'truth'. Edna actually commented on the complexities of trying to 'protect' others in some way, she said:

> You spare those people you love the best, well you try to, but in doing so you're rejecting their love for you. And that didn't dawn on me until [a friend] died. Her mam weren't brought in right until the very very end and she didn't know how bad things were, and that's what I've done with my mam. I suppose I think I'm sparing her, but she's probably sitting over there thinking, "Well what isn't she telling me?"

This desire to 'protect' others should not been seen purely in terms of being representative of the selfless or sacrificial character of the 'heroic death'. As mentioned in the previous chapter avoiding discussing the subjects of cancer and dying is advantageous to all parties, thus it follows that at times emotional work itself 'protects' both people involved in an interaction. For example, Gaynor said:

> ....I think why say it. It's not going to help me, so I tend not to, it doesn't bother me, but then again am I selfish not asking them? You know am I trying to protect them that much that perhaps they want to talk and I don't want to.

Emotional work was used at times solely to protect respondents themselves, rather than others, as they struggled to avoid talking about issues they found too difficult. This was the case for Ann, who acknowledged that her desire not to talk about her disease was not really what her husband wanted, and it actually confused him. It would seem rather that her emotional work was designed to protect herself from a situation she found difficult to deal with:

> I'm keeping everyone away and I'm not talking about it, poor old Geoff [husband] doesn't know where he is, it's a shame.

Ruth's experience also seems to accord with this desire to 'protect' oneself, rather than others. For example, she felt that she did not want the 'responsibility' of having to deal with people and cope with their reactions, therefore if possible she avoided telling people her diagnosis. She said;

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....because it's some sort of responsibility when you tell people because you're giving them some bad news to cope with, I have been aware of that. That's why I avoid telling people unless I have to.

However, it was not only the dying themselves who were involved with emotional work. In Rachel's case, she felt that her avoidance of the subject was beneficial for her husband, but similarly appreciated his efforts to avoid the topic too, she said:

> ...but in one sense I'm trying to protect him and he's protecting me. I don't know whether that makes sense.

Although emotional work often ostensibly seems to be done for the benefit of others, it is interesting to see that when respondents' families and friends did not acknowledge, or more importantly appreciate the work they were doing they sometimes became annoyed. Such attitudes would seem to question Seale's (1995a) presentation of emotional work as purely sacrificial. It would seem that although respondents did indeed want their loved ones to feel comfortable around them, they wanted their work to be successful because it made their own lives a little easier, and when their emotional work failed to be recognised, or failed in some way, it seemed that they were 'wasting their time'. Katie, in particular spoke about how she resented the fact that her labours appeared to be to little or no avail:

> I thought that by carrying out a normal routine, when I can, that I would take the pressure off them because they can see that I'm still good, that I'm still the same mum. So, it's not as though every minute they walk through the door it's, "I've got cancer, and I don't feel well today." I never discuss it with them, they say, "How are you?" And I say, "Fine, thanks," even if I'm in pain and feel rotten she's [daughter] on the other end of the phone, it'll pass so I always say I'm good.

And later:

> I really feel as though I've been used as an excuse and then I think, "Hang on if it was my mother I'd feel the same," I don't know. But I've never used my condition as an excuse. I've never said, "Sorry I can't do my shopping because I'm not well enough," I've never said, "I can't do this because I'm not well enough."....I hope I've never given people the impression that I'm feeling sorry for myself or anything. I just want to get on with it, nothing can be done about it. And I thought that was how the kids felt. But all of a sudden I'm giving Mike [son] stress enough to lose weight, I'm giving Gina [daughter] enough stress that it's put stress on her marriage and over eating. You know half of me feels very cross and half of me feels guilty. And I feel so low about it, I thought, you know the sooner I go the better because I'm really brassed off with all this, that's how I really felt about it. I felt I'm between the devil and the deep blue sea.

However, individuals did not necessarily always try to make things easier for other people. Katie's experience also highlights this. She had always had an acrimonious relationship with her mother-in-law but, had tried to keep the relationship as friendly as possible in the past. Now, she felt that she no longer wanted to waste her time and effort on someone she did not care about. She said:

> She [mother-in-law] wants to be included, she feels like I'm pushing her out of our lives. It's very hard, it puts Steve [husband] in a very awkward position. But I think, what the hell, I'm dying, why can't I for the first time in my life turn around and say what I feel, you know. Why should I have to pretend, to pussy foot, to save her feelings when she's given out so much flack?

Emotional work is not unconditional. Like all work individuals appeared to weigh up the benefits for both themselves and others, against the input required of them. When the effort outweighed the benefits in terms of having to spend time and energy trying to protect people who were not particularly dear, then emotional work was not a central part of such social interaction.

Dying places significant demands on the individual, both physically and in terms of the emotional work which appears to be necessary at this time. Gail found both the physical and emotional affects of her dying difficult to deal with at times, although it seemed that she was resigned to these things:

> It's all quite hard, but I mean it's hard when you sort of see your parents you know, what they sort of go through. Upset me losing my job, but I don't feel bitter, you know it's just one of those things.

Not only were the 'obvious' effects of dying difficult to manage but the very process of coming to terms with one's mortality, and trying to construct some meaningful narrative from the process, was also demanding.

> ...one reason why the work of the dying seems so difficult today is that individuals are expected not only to confront their own death - in itself a task arduous enough - but also to *create* a death out of the fragments of ideologies and religious sentiments with which our culture provides us. (Hawkins,1990/1,303-4)

The emotional work involved in both the management of social relationships and the negotiation of the individual's self-identity requires a great deal of time and effort.

> Emotional labour is hard work and can be sorrowful and difficult, it demands that the labourer gives personal attention which means they must give something of themselves, not just a formulaic response. (James,1989,19)

It is ironic then that at a time when respondents often referred to others telling them to rest and 'take things easy' that they should be involved with emotional work. Anna said,

> It's very hard to think that you are actually facing a death sentence, which is what it is now, and I've never felt like that before. And it is hard, and it's hard trying to in your own little way trying to sort things out for the family to get them ready for it and that, you know.

and later

> I mean it's very hard to talk about things, however much you try and be in control and say that I want you to do this, and, I want you to do that. It's hard to actually say it without a lump in your throat.

Emotional labour is hard work and dying itself is hard work; nothing in the process is fixed; the only certainty is its outcome (Hawkins,1990/1).

Grieving and leaving: After-death identities

Respondents' emotional work often also involved grieving. Engel (1961, cited in Crookes, 1996) argues that grief is a characteristic response to the loss of a valued object, possession, status or ideal. In this instance individuals were to a lesser or greater extent all involved in grieving for both what was occurring at that particular moment, in terms of the loss or reduction of their traditional roles; and also for the future - the life they would not have, the relationships which would end. While grieving for these things, it should be noted that death does sometimes also offer a 'release' for some individuals. For example, in her second interview in the hospice Liz said:

> I was physically ill, mentally ready to pop my clogs, I really was. And I still am to be honest..... I've struggled so long, you know two and a half years, well more than two and a half years, that might not seem long, but when you're going through it that's a long time.

This accords with Hinton's view:

> ...a sense of peace and pleasure may attend the recognition that some struggles and unpleasant features of living have now ceased....[This] may be a relief that, say a lonely life of continual ill health need not be endured much longer. (1984,235)

Grieving is more generally a process which is associated with the bereaved. Walter suggests that the purpose of the bereaved's grief is:

> .....not to move on without those who have died, but to find a place for them. For this place to be secure, the image of the dead normally has to be reasonably accurate; shared by others and tested against them. (1996,20)

Marshall (1980) asserts that individuals in old age often reflect on their lives, metaphorically writing their own 'last chapters'; in which they order and make sense of past relationships and events. However, Walter (1996) argues that it is the friends of the deceased who, during the course of their bereavement, write their loved one's 'last chapters', by constructing and modifying the memories they have of them. They do this on an individual basis, but also in the course of talking to other people about their loved one. Through such social interchange they negotiate and modify the memory they hold of the dead. I would suggest that while survivors may indeed be engaged in a process of negotiating a new after-death role or memory for the dead, individuals themselves actively contributed to the memories they left behind, and as such should be viewed as 'co-authors' in their last chapters. The emotional work concerned with preparing their family for life after their death, often also involved individuals contributing to the construction of their after-death identities. Unruh acknowledges the importance of the efforts of the dying in this process:

> This emotional attachment [of the survivor to the deceased] is reinforced by actions on the part of people before they die.....Dying people hope they will be remembered as good fathers, competent mothers, successful business men, creative artists or peacemakers. Survivors are left with bundles of images, material objects and wishes of the deceased. (1983,340)

What remains after death is not an empty page on which survivors can write their 'last chapters' but rather it would seem that the dying leave behind fragments of their self-identities which they hope others will pick up and elaborate on in order to continue the process of constructing their after-death identities. Contributing to one's memory in this way stands in stark contrast to 'social death' (Sudnow,1967) because in the case of my respondents it would seem that some hoped to maintain 'social life' even after biological death. This seemed to be particularly apparent when they discussed the provisions they had made for dealing with their death. Before considering the

plans individuals made for their deaths, it should be noted that not everyone spoke explicitly about their hopes for what would happen after their death - in terms of funeral arrangements and how their families would cope - because clearly this was an extremely emotive and, for some, distressing topic. I only pursued conversations about death with those respondents who themselves introduced the topic. However, many individuals did talk more implicitly about death, when they discussed the need to leave happy memories behind, and some did discuss the ways they hoped others would remember them, which can be seen as part of a process of negotiating an after-death identity.

Respondents were obviously aware that their family and friends would continue life without them after their death, and some of their emotional work was designed to prepare their family for life without them. It is interesting that the emotional work connected with the individual's actual death, as with nursing, often involved more practical tasks such as paying for funerals and making wills. Despite the practical nature of such preparations this effort still constitutes emotional work because often talking about and making such plans was very distressing for both individuals and their families. Emotional work was necessary to minimise and manage such distress in order to achieve the desired end. Some respondents had special photographs taken on the back of which they wrote messages, others made tapes and videos; and some, particularly those with young children, constructed 'memory boxes' containing significant objects, letters and sometimes stories; all of this was emotional work. It would seem that such behaviour was also a way for respondents to try in a practical way to ease the pain of bereavement by giving their families keepsakes which they hoped would be of some consolation to them after.

> They had some photos they can pick their own, one or two out and we've had them made a bit bigger and I shall just put a little note on the back of them or something, you know with lots of love. I mean in a way what I should be doing is making a double tape this afternoon and letting the children have one and you have one. Andrew [husband] did bring a tape recorder home. It's very hard though for me to try and do it, I don't know what I'm going to be able to achieve. (Anna)

Judy, like others, tried to limit some of the distress her family would have by sorting out some practical things before her death.

> I wanted to plan so that it would be a lot easier for them.... I thought I don't want to leave my family with the confusion, with the muddle, with the mess that I've seen in others. I said to my two, "Now we're home I want you to go round the house and just say what you want." I've got quite a bit of jewellery and....I said, "You know you decide now what you want."

Such practicalities are an important part of constructing one's after-death identity:

> Wills and testaments are the most obvious devices used by the dying to apportion and disperse objects in which personal identities and feelings about oneself are shared..... Disinheritance, the other side of the issue, also preserves identities. Conscious exclusion of an award to legal heirs demonstrates assertiveness, independence, or publicly metes out punishment. (Unruh,1983 344-5)

Planning funerals also enabled individuals to influence life after their death and, consequently, contribute to their identity beyond the grave. Although individuals tended to speak about their plans as being designed to assist their families and friends during their bereavement, it is clear that such plans also served to reaffirm the individual's self-identity after death.

> I've been to see the gravestone and it's only small and there's two people in there already...but my uncle's not been written on the gravestone...[and] there's not enough room on the gravestone for three names. So what I've decided now you know you can get those open books well I'm going to have one of those on my own with my picture on it and put it in front of the gravestone that's there now. Plus, I said to my mum, "If people want to bring flowers then you shouldn't say no Sarah doesn't want any flowers just let them bring them."

Letters, tapes, photographs or simply trying to create 'happy memories' was a way for respondents to try to ensure that they were remembered in the way they wanted. Clearly, however, some of the emotional work which took place in terms of trying to leave behind 'happy memories' was sometimes less outwardly visible. This can be seen in the case of Sarah, she made plans for her son's birthday, which were concerned with giving him something to remember. She said:

> Alex [son] wants a bloody magician or something on his birthday party this year, and I know when he goes to live with my mum she won't be able to afford to have these things. I don't know how much these things cost, but I know they're a little bit of money for a couple of hours. So I thought if I pull my belt a little bit tighter he'll have that now and then at least he can say, "Oh on my seventh birthday I had a magician." Because he'll never get things like that at my mum's house.

Similarly Katie said.

> I wanted to have a good Christmas so the family had good memories, I didn't want to be bored and sick and not able to do the Christmas dinner or the whole Christmas thing that went with it. I want them to be left with good memories.

Individuals were obviously concerned about how their deaths would affect their families and often tried to talk to them about this. For example Anna said:

> I've told them that they must all pull together and help each other and get settled really, finish off what I've done.

As Charmaz (1997) notes the self-identities of significant others are also affected by the death of a loved one. Relationships are one way in which we construct and define ourselves and how others perceive us, therefore losing a partner leads to a change in one's self-identity, for example a change from husband to widower. Some respondents spoke about their concerns for their partners, and the fact that they hoped that eventually they would 'find someone else'. Anna said:

> I've told my husband I want him to remarry, I've told him he's got to wait a decent time though, not got to rush off and do it in three months, he mustn't go off the rails, he must wait a year or so! I just want them to be happy, I mean I don't want them to ever forget me, or anything, but I don't want them to grieve for me for years and years...Yes, I really am a mother, a Jewish mother as they say!

Conversations of this nature were clearly difficult, but as already noted the use of humour was one way in which individuals were able to manage the situation and ensure their wishes were known.

In considering how an individual's identity would continue after death it is interesting to note that few respondents spoke explicitly about their faith in an afterlife. Only Judy alluded to any strong religious belief, she said:

> I wouldn't be able to go through this if I didn't have a strong faith, it's my faith that keeps me going.

Others tended to speak about any after life in more ambivalent terms, for example, hoping that there was 'something' there, or believing there to be 'something' but not quite sure what it would be. This is apparent from the statements below:

..it helps me to think that there is something there when you go rather than nothing, because in that way it helps me with the thought of dying. But I think hang on I've got a ready made family there....So I feel as if I'm losing one family for another. So, goodness knows what happens if it's not true, but it'll be too late then won't it? So whether it's false illusion or whatever, but it helps me. (Katie)

I think there's something after I don't know what, I think there's something after. Like you leave your body and then it's just an empty shell. (Sarah)

....some people have such wonderful faith, that there is [something else after death]. I mean, I like to think that there is a better life after this. I don't know, I don't know. (Anna)

Such quotes suggest that respondents felt that they would not be aware of anything after death - implying a division of body and self-identity. Copp noticed the same trend in her respondents:

Patients' separation of the personal self from the body seemed to occur when talking about their disease, symptoms, or as part of funeral arrangements. (1997,8)

What would happen to their bodies it seemed, to some extent, was of little concern because it was no longer of any use to them, and their existence now relied upon the work of other people in sustaining the 'last chapters' they themselves had helped to 'write'.

Any discussion about a post-death identity seems to challenge the notion that the body and self-identity are intrinsically linked. It seems that the dying actually separated two, because although they existed within a failing physical shell their identities had the potential to exist outside and beyond the confines of this space.

Instead of being one body they were two, a body which was afflicted and a mind that looked on. (Young & Cullen,1996,39)

Copp (1997) in her work notes that this separation of the self and body was apparent in both patients' and nurses' accounts of deaths in a hospice environment. With regard to patient's views she says:

It is likely that individuals construct this separateness as part of the process of ensuring a sense of continuity and meaning after death. For although embodiment of self (i.e. personhood) makes a person unique during life, death is finite in terms of bodily human existence. What remains is essentially a body and memories about an individual. An absence of a 'separation' would constitute the total annihilation of the person; body and self. (Copp,1997,10)

This separation has been also been evident elsewhere when individuals continued to reaffirm and renegotiate their self-identifies, even when their physical state had deteriorated to such an extent that they could no longer do the tasks associated normally with those roles:

> The spirit did not need to weaken as the body weakened but could get stronger. The spirit was something to hold on to, to be held up by and to be stubbornly proud of. The spirit was relatively timeless - the continuo above which the solemn and the gay were played out. The spirit was not their body; it was what made them more than a body. (Young & Cullen,1992,62)

This gradual shift away from the body as central to the maintenance or self-identity can be seen in this context as a preparation for the ultimate separation of mind and body - death. Respondents' identities as parents, partners and friends would continue long after their bodily demise if they were successful in making a mind-body separation during their life. While emotional work was an important feature of respondents dying it did not only benefit them before death. The emotional work individuals engaged with throughout their illness was obviously important in establishing this divide, as they negotiated their changing and evolving self-identities. However, such work was also important for their after-death identities. To this extent the 'heroic deaths' which the bereaved may reflect on after their loved one's death was not a product of purely selfless or sacrificial emotional work, but rather such work was a conscious attempt to maintain some status in people's lives after bodily demise.

Conclusion

In this final section of my thesis I reflect upon the preceding chapters, and consider the main issues which have emerged from my research. The aim of this thesis was to explore the experiences of living with a terminal illness from the dying individual's perspective. My discussion therefore, unlike other research in the area, is purely devoted to examining this one perspective, rather than either health professionals' or lay carers' experiences (cf. Addington-Hall *et al*,1991; Cline,1995; Young & Cullen,1996; Young *et al*,1998). Further, although other research has been conducted solely with dying cancer patients, my research differs in its approach (cf. Kellehear,1990; McLean,1993). In my study I used a qualitative approach, which allowed me to explore solely individuals' views and experiences in depth. The use of focused interviews allowed respondents to discuss those aspects of their lives which were important to them. My thesis reflects these individuals' experiences, and while I have divided my discussion into four discrete data chapters, it is important to recognise that there are overlaps and commonalities between these different sections. My discussion therefore is cumulative in nature, the thesis must be considered as a whole in order to get a complete view of respondents' lives.

Although my thesis is an academic piece of work, in my introduction I stated that I hoped my discussion would be of interest to a wider audience beyond social science. I also said that I believe sociology, should be viewed as more than an academic discipline, because the sociologist has a role to play in facilitating change both through exposing short-comings in existing practice, and challenging taken for granted assumptions. To quote Giddens again:

> The practical impact of the social sciences is both profound and inescapable. Modern societies, together with the organizations that compose and straddle them, are like learning machines, imbibing information in order to regularise their mastery of themselves..... Only societies reflexively capable of modifying their institutions in the face of accelerated social change will be able to confront the future with any confidence. Sociology is the prime medium of such reflexivity. (1987,21)

As I reflect on my thesis and the research process I feel that respondents' accounts raise a number of important theoretical and empirical issues. Given this, I believe that my discussion is of relevance to social scientists, health professionals and those people generally interested in the care and experiences of the dying.

Before considering the central themes and concerns of my thesis, it is important to note once again that respondents were all living and dying within a particular time and culture, and their experiences were shaped by the dominant views and expectations of wider society. Historically, people commonly died younger and death was sudden, frequently a result of acute infectious diseases. Today, general improvements in public health and hygiene have meant that individuals are now living much longer, and death is now more commonly the result of long term degenerative chronic illness. In the first chapter I considered the ways in which the management of dying and death has changed over time. Death itself has become institutionalised and professionalised, and although much of the dying process still takes place within the home, people's final days and weeks are usually spent in health care institutions, sequestered away from 'normal' society. Further, increased longevity has meant that death and bereavement are experiences the majority of us do not expect to face, at a close personal level, until adulthood. Today, individual deaths generally have little impact on the wider community. Death is now associated more commonly with the elderly, who have lower 'social loss' (Glaser,1966), because as people age their social worth to society gradually declines. Individual deaths only appear to have an impact on wider society when they are associated with either a tragedy, or when they are the deaths of someone who has high 'social loss'.

Earlier I also considered the debate, particularly within sociology, about the extent to which death can be seen as 'taboo' in contemporary British society. While the prevalence of published academic work and extensive media coverage of death would point to the lack of a 'taboo', it should be noted that:

> Despite the resurgence of academic and religious interest in the subject, as a society we remain uncomfortable with the facts of mortality. (Mellor & Shilling, 1993,423)

More specifically it seems that such coverage does not equip individuals within society to deal with dying and death at a personal level. Therefore, I would agree with Walter *et* al's (1995) assertion that although dying and death are visible in the public sphere, they remain 'privately absent', to the extent that at an individual level dying and death are difficult to deal with. Further, it appears, there is no longer a commonly available, coherent language available to talk about death, resulting in conversational unease and embarrassment at the individual level (Walter,1994). What seems to be apparent in contemporary British society, is that the dying and dead are marginalised and devalued. It is against this 'back drop' respondents lived out their lives, and this should be borne in mind when considering the ways in which they managed and renegotiated their self-identities at this time. When dying and death do exist in the private sphere they present particular difficulties and dilemmas for both the dying themselves, and their significant others. However, the focus of my research and thesis is the individual living with dying. My concern throughout has been to explore respondents' experiences at this time, and to consider how they managed and negotiated their self-identities.

My thesis is structured by respondents' accounts, and my consideration of both the private and public reflects the relevance of these spheres in those accounts. A diagnosis of cancer means that at least some of a person's time will be spent in medical encounters, although much of their time and the majority of their dying will actually take place within the home. This is particularly important because it reiterates the point that while individuals were 'patients' at the local hospital or hospice, within the home where they spent most of their time, they continued to fulfil the same roles and responsibilities they had for many years. I feel that the analogy of a play is a useful way to present individuals' lives, because their lives were made up of different 'scenes'. Just as watching only one scene from a play may give a partial and inaccurate view, the same is true if attention is only given to one aspect of respondents' lives. Therefore it is imperative that all the 'scenes' in their lives are seen as a whole in conjunction with each other, in order to understand

the complexities of individuals' lives. However, it is also important to note that 'backstage' there are likely to have been areas to which I was not permitted, and which therefore remain hidden.

Individuals had 'simultaneous multiplicity of selves' (Goffman,1978). What emerged from respondents' interviews was their desire to maintain these existing complex roles and responsibilities for as long as possible. When they were no longer able to do this, they tried to modify and renegotiate existing roles. The maintenance and management of self-identity became the central tenet of my thesis; and intrinsically bound up with this is the concept of control. In both the public or private sphere individuals had to manage their social relationships in ways which seemed appropriate to them. Sometimes they asserted control over the encounter they found themselves in, at other times they were prepared to allow other people to take control. This relinquishing of control took place particularly in medical encounters when respondents placed their trust in professionals' knowledge and expertise. However, what becomes apparent from respondents' accounts is that whatever course of action they decided upon, their decisions seemed meaningful to them within the context of their own lives.

Although all my respondents had been referred to LOROS for one of its services, this thesis is not about the experiences of being a hospice patient. Whilst some parts of respondents' accounts did reflect on this aspect of their care, the majority of their 'stories' were concerned with care received in other institutions, and their lives outside the role of 'patient'. All the respondents in my study group had been diagnosed with cancer. However, I believe that their accounts are likely to hold meaning for other people dying of long term degenerative chronic illness - accepting that such people may not have access to the same kind of information or services as someone dying of cancer. As respondents were all under the age of 67 some of their experiences may be age specific - for example, managing the fact that one is likely to die before one's parents, or arranging care for young children after one's death. However, again this does not mean that my thesis only holds relevance for people of a similar age, rather I would suggest that their experiences at this time

reflect those of other older dying people, but this group may experience some aspects of dying differently because of their age.

Reflecting upon the fieldwork process and the writing of this thesis generated mixed and contradictory emotions. As I write this final section it is important to reiterate my gratitude to respondents for giving me so much of their limited time for little, if nothing, in return. Although I recollect many positive and inspiring things respondents said, this is tinged with feelings of sadness, because so many of the people I spoke with are now dead. The emotional work of respondents' was a particularly important part of their lives, and necessary to managing their self-identities. However, it is important to recognise that emotional work is also an intrinsic part of the academic process itself, although it is often neglected or ignored in written accounts. To say that researchers themselves engage in emotional work during the course of their fieldwork is perhaps quite easily understood. However, such emotional work does not end when data gathering ceases, rather, I would suggest from my own experience, it also remains an important feature afterwards. Like Cannon (1988) I feel it may be too dramatic to say my research and writing this thesis has 'changed my life'. However, it has certainly had a significant impact on my own understandings and attitudes towards living and life, dying and death. Without doubt there are words and images which will remain with me always.

Living with dying: issues of negotiation and control

It is important here to reiterate some of the most important issues to arise from my study. In this section of my thesis, although I still discuss issues pertinent specifically to the public and private sphere, I do not separate them as discretely as elsewhere. I do this in an attempt to draw together the different aspects of respondents' lives. Respondents were indeed 'patients' for a significant proportion of their lives at this time, but the majority of their time was not spent in hospitals but in the familiar surroundings of home, where they had other more valued roles and responsibilities.

The whole thesis has considered the ways in which a diagnosis of cancer, and a terminal prognosis affects an individual's life and self-identity. Cancer remains a metaphor for death. Given this, becoming a 'cancer patient' who is 'dying' is an unwanted status change, and yet, as I have discussed, it often becomes an individual's master status in the eyes of others; a diagnosis of cancer changes everything. All respondents alluded to their belief that they now had a 'spoiled identity' because of their cancer and dying status, indeed many felt that having cancer was a 'stigma' (Goffman,1990b). They perceived that others either avoided them, or felt 'awkward' in their company, because of their diagnosis. Earlier I discussed the ways in which social death can occur before biological death, and to some extent individuals experienced this when some significant others avoided them. However, the fact that such avoidance, or difficulty in social interaction, was far from consistent suggests that it may be necessary to conceive of 'social death' as changeable over time and between different encounters. Just as the dead may be 'dead' to one individual and 'socially alive' to the next (Mulkay & Ernst,1991), so too for the dying. Some people continued to visit, but at the same time others avoided contact with them. Therefore at any one time they had contradictory experiences of social life and social death. In respondents' lives it did not seem that there was a moment when all their significant others reacted towards them in the same way.

The notion of cancer and dying as a stigma can be further understood, by considering two important points related to the position of the dying in contemporary British society. Firstly, we live in a society in which individuals are encouraged to plan and structure their own future (Mellor & Shilling,1993). Secondly, within this future-oriented community a 'culture of the body' prevails, where youth and health appear to be prized beyond all else (Featherstone,1982). Individuals are increasingly encouraged to invest in the project of their body, and at the same time death is increasingly reduced to individual causes and by implication, individual failings. There is a moral imperative for us to take responsibility for our own health. In such a culture the dying, particularly those perceived to be 'blameless', present a major challenge to dominant beliefs and

values. Dying means that one is no longer able to engage in the process of planning and structuring the future in the same way as others, because death logically represents no future.

> The process of dying.........cannot be seen as anything other than the incipient loss of control: death is unintelligible exactly because it is the point zero at which control lapses. (Giddens,1991,203)

In addition to this, the dying remind others of the fallibility of the human form. When death is associated with older, frailer bodies, it is easier for other people to dismiss and forget about its existence. However when dying and death lurk in 'young', seemingly 'healthy' bodies, people who 'should not' be dying, this presents a major personal challenge to others, and demands that they also confront their own mortality.

Given the above, it seems appropriate to conceive of the dying using Simmel's concept of the 'stranger', someone who is both part of a group and yet outside of it. (Wolff,1950). The dying are 'outsiders', because although in many ways they still fulfil the same roles and responsibilities they always have, their dying status places them outside the experiences of the wider community. An initial diagnosis of cancer, and later a terminal prognosis, had a profound effect on individuals' self-identities. Therefore, it was necessary for them to reassert their more valued roles and responsibilities, if they were to continue to occupy meaningful positions in people's lives. Respondents engaged in 'role distancing' (Goffman,1978) at times, whereby they concentrated upon aspects of their identity which detracted from their status of dying. On other occasions individuals engaged in both 'passing' and 'covering' (Goffman,1990b); their main concern was to maintain their social worth in others' lives for as long as possible. They achieved this by detracting attention away, as much as possible, from their cancer and dying status and focusing on the things they were still able to do, and the roles they were still able to fulfil (even if these had to be modified).

Individuals managed their cancer and dying status in a variety of ways, and I have shown that the role of emotional work was crucial in this management. Emotional work was the work individuals

engaged with in order to manage the feelings and emotions of both themselves and others. At times it meant keeping the situation 'light', at other times it meant trying to 'play down' their symptoms, and on occasions it was just about trying to make 'happy memories'. The fundamental purpose of emotional work was to emphasise their status of 'living', and as such it served to emphasise that respondents were not one-dimensional, rather they had a 'a multiplicity of selves'. Much of the research on emotional work to date, has concentrated on the emotional work undertaken by paid and unpaid carers (e.g. Strauss *et al*,1982; James,1989,1991; Smith,1990). While it is clearly important to recognise and understand the role of carers' emotional work, I believe that the same work undertaken by dying individuals themselves has been overlooked. Such work was imperative to the maintenance and negotiation of self-identity at this time. Given this, I have argued that the emotional work of the dying did not only serve to help others, but it actually had benefits for individuals themselves.

A diagnosis of cancer means that much of an individual's time will be spent in different health care environments: consulting health professionals and undergoing and recovering form various treatments. With regard to their experiences of health care, respondents made a number of important points. It is apparent from my discussion that individuals' biographies are important to their understandings and experiences of their disease and treatments, and locating these in the context of personal biography is obviously important to self-identity. For example, when respondents discussed the reasons for the genesis of their disease, they looked at their own experiences to make sense of why this might have happened to them, but they often emphasised how events or circumstances out of their control were also responsible. Such explanations highlight a number of points. Firstly, they show the ways in which medical understandings have been adopted, and sometimes reinterpreted, by 'lay' understandings of disease causation. Secondly, they show that respondents hoped to be seen as 'blameless'; to be labelled as being 'responsible' for the causation of their disease would have had a negative impact on the way in which others perceived them, and consequently on their own self-identity. Thirdly, such

explanations show how important it was for individuals to make sense of what was happening to them within their own life-histories, biomedical explanations were rarely enough.

One issue which individuals often remarked upon was the way in which they were given information about their disease, and the way in which they interacted with medical staff generally. For example, often they only consulted their GP after a period of time. They reflected on what was going on in their own lives at that moment, in order to find other explanations for the way they were feeling, before deciding whether to seek medical attention. As respondents often went through this process before consulting their GPs, to have their fears dismissed, or ignored, was for some very difficult. When GPs told other respondents there was 'nothing wrong' they believed this, and went away reassured. However, having to return to the GP again later often caused further distress. Difficulties with medical encounters also occurred when individuals were referred to hospitals. There has been considerable debate, and shifts in practice, with regard to disclosing diagnoses to patients, and the current trend appears to favour telling patients. While some respondents did not comment on the way they were told, others reflected on vague conversations, when they felt they were being encouraged to 'read between the lines'. For others it was not that they were not told their diagnoses, but rather that they had trouble deciphering the medical language doctors used. They often only picked up what was being told to them because they recognised certain words, or parts of words and phrases.

Time was a particularly important feature in respondents' experiences. Firstly, at a fundamental level many of them now had 'limited time' left. However, in other ways time played an important role in informing both their views of, and relationships with, health professionals. Too much time it seems was spent waiting in out-patients, waiting for test results, having treatment, and waiting to see their doctors. Conversely, respondents often commented that not enough time was available for them to talk to their doctors about their concerns. While respondents were ultimately very forgiving of what they perceived as professionals' failings in their interactions with them, the lack

of time available for each patient did have other consequences. When respondents left encounters feeling confused or dismissed this affected their view of that doctor, but more importantly it had the potential to undermine their feelings of being 'in control'. However, as I have discussed patients should not necessarily be seen as powerless in medical encounters. For example, some individuals decided to learn more about their disease in order to communicate more effectively with staff. Given this it seems that it is necessary to conceive of the patient-doctor encounter as a 'meeting between experts' (Tuckett *et al*,1985). Appropriate attention must be paid to individuals' own understandings and experiences of their disease, because it is they who live it.

Control - its maintenance, lack and renegotiation - is an important feature of individuals' experiences of living with cancer. Being diagnosed with cancer itself made people feel 'out of control'. There was something inside them which was growing, 'invading' their bodies, and more importantly up until the point of diagnosis it had been doing so undetected, their bodies had 'let them down'. Not only were respondents' bodies 'invaded' by cancer, but they also endured 'counter-fire' from surgery and treatment. During the course of their encounters with health professionals many individuals relinquished some control; in this particular social setting being a 'cancer patient' became their master status. Doctors made the decisions about what treatment they should have, other health staff administered this, and respondents complied with such advice. Individuals were prepared to accept such limitation to their own control because they hoped there would be benefits from this, the ultimate aim being that they would be 'cured' and they could therefore resume their normal life again.

When recovery was no longer possible some people decided that rather than continuing to be tied to hospital appointments, and having to endure potential treatment side-effects, they would prefer to live their remaining time as free as possible from further medical interventions. Deciding not to have any/more treatment was a particularly difficult decision to make, because while, to a great extent, it freed respondents from the role of 'hospital patient', other people appeared to not always

agree with their decisions. It seems from individuals' accounts that health professionals, in particular, expect cancer patients to conform to certain expectations. Medical staff appear to expect patients to continue to try certain treatments, until they, the professionals, decide this is no longer appropriate. The patient who fails to conform to these expectations may be labelled as 'difficult' or 'giving in'. My thesis shows how such an interpretation is inappropriate. Patients are rational; they make decisions within the context of their own lives, experiences and understandings. Despite this respondents were aware of others' expectations of them, and consequently they justified their decision to not have any/more treatment, just as they sought to absolve themselves of responsibility for 'causing' their disease. They took the time to point out how they were not being 'irrational', but rather they had made an informed choice between: perhaps more time with treatment and side-effects, or limited time, with what they perceived to be 'quality of life'. Clearly choosing to not have any/more treatment has implications for self-identity. It allowed individuals to reject many aspects of the 'cancer patient' role, thus giving them more 'space' (Lofland,1978) in their lives to emphasise other important self-identities. Although there are clearly positive gains to be made from limiting the amount of life 'space' given over to 'cancer', such rejection of treatment had to be carefully managed if the individual's self-identity was not to be damaged by others regarding them as being 'difficult' or 'irresponsible'.

As so much of respondents' time was spent waiting in different health care settings, invariably they came into contact with others with similar diagnoses. Such encounters again had particular implications for individuals' self-identities. Constant contact with others in a similar situation was rewarding for some people, indeed it encouraged them to feel better about their own lives, because they compared themselves to others in a similar position and they realised they were doing 'better'. 'Vying for a winning position' in this way (Forsyth et al,1984), or 'gaining a sense of mastery' (Taylor,1983), were particularly important if individuals were to gain something positive from their experience. This was particularly apparent when respondents spoke about the

advantages of dying of cancer, often comparing it favourably with dying suddenly, as a result of a heart attack. However, contact with others with similar diagnoses also had potentially damaging consequences. For example, it could mean that individuals suffered from 'stigma contagion' (Goffman,1990b) if they spent too much time with those who were more obviously ill than themselves. Given this, one 'survival strategy' (Bauman,1992) individuals used was to avoid particular people at certain times. This was not only a 'survival strategy' to the extent it prevented respondents from having any further drains on their limited emotional resources, but by distancing themselves from others with similar diagnoses in this way, it allowed them to emphasise other aspects of their multi-dimensional identities.

Respondents were pragmatic. This was particularly apparent when they discussed their deaths. When examining academic and popular literature and media representations there are many varied images of death:

> Death is not terrible. One passes into dreaming and the world vanishes - if all goes well. Terrible can be the pain of the dying, terrible, too, the loss of the living when a beloved person dies. (Elias,185,66)

> The illusion one holds about a peaceful, dignified death and the family's perfect bedside farewell will almost certainly be tugged away. Dying is nasty, ugly, painful. It's so obvious, isn't it? (Picardie & Seaton,1997,23)

Each individual who spoke about dying and death had their own particular hopes and fears. While there were some commonalities between the descriptions respondents gave, each image was individual and personal, and had relevance to their own biographies. However, the most important fact to emerge from their accounts was that people seemed to be prepared to accept a 'good enough' death. While dying at home may have been some people's ideal, they recognised that in the event this may not be possible. They wanted this part of their dying to be as acceptable as possible to everyone around them, given the circumstances in which they found themselves at the time; they were prepared to compromise their own hopes and ideals. My study has shown that a rigid interpretation of the Good Death appears inappropriate in the light of respondents' accounts. McNamara (1998) notes how the Good Death as a concept may be too idealised in reality for

health professionals. However, my study shows how for dying individuals themselves a more flexible notion of the 'good enough' death is also required. Such a concept recognises and allows for individual variations and caveats, and prevents patients from being labelled 'good' or bad', because in the more subjective 'good enough' death no one else can make these value judgements. Further, I suggest that the 'good enough' death has advantages for health professionals themselves, because where as 'failing' to achieve a Good Death may leave staff feeling demoralised, the 'good enough' death does not have the same goals which have to met; what is 'good' for one individual may not necessarily be so for the next.

Although control is important throughout every aspect of respondents' lives, it is interesting to note that they were actually prepared to relinquish some control in the event of their deaths; to accept 'good enough'. However, up until this point, and beyond, having some kind of influence or control remained important. This control meant that respondents were able to reassert and negotiate their identities. With reference to their deaths, I have shown that one of the functions of respondents' emotional work was to contribute to their after-death identity. Loved ones may indeed have ultimately reflected upon their 'heroic' dying and deaths, but it is imperative to note that the emotional work employed at this time was not selfless in character as Seale (1995a) suggests. Rather, I have shown how it had advantages for individuals themselves, in terms of contributing to their future post-death identity; respondents themselves gained and benefited from their emotional work. The role of individuals themselves in contributing to their own after-death identities is a particular important point. Previous work has suggested that it is the friends and family of the dead who 'write' their 'last chapters' (cf. Walter,1996). My study illustrates how the dying are in fact 'co-authors' in these 'last chapters'. They use their emotional work to contribute to the memories they will leave behind; they leave 'cues' for others to build upon in the future. Sometimes the emotional work at this time involved physically leaving momentoes behind by which others could remember them, such as letters or photographs. At other times this meant individuals engaged in the more abstract process of trying to leave 'good' memories behind.

Planning funerals, and leaving wills and directives, was also another way they hoped to ensure they would be remembered in a certain way. To some extent this thesis also contributes to respondents' after-death identities, because although they are to the majority of people anonymous, their words and experiences continue to have an impact even after their deaths.

The fact that individuals seemed to plan for their after-death identities has two implications. Firstly, it shows that although other research has illustrated how social life continues after biological death, the dying themselves appear to actively contribute to this process. The irony is that while some people ignored or avoided them, that is they experienced some of the characteristics of 'social death', at the same time they were planning for their 'social life' to continue after their deaths. Clearly some of this is related to respondents' active roles in rearing children, and the fact that many of them had spouses they would leave behind. Given this, it was important to individuals to let their loved ones know what they hoped for them after they died. The second point implicit in the notion of an after-death identity is that the physical body and an individual's concept of self-identity are not intrinsically bound. Respondents were clearly able to conceive of themselves in a 'disembodied' form (Turner,1995); they separated their self-identities from their physical form. It may be argued that the separation of the physical body and self-identity began for some when they first realised their bodies had failed to give them any sign of the 'invasion' of cancer. However, as individuals' physical capabilities decreased this separation became more apparent. As this occurred they invested more time in managing the aspects of their self-identity which did not demand much from their bodies. They invested time in relationships. They detracted attention away from their failing physical forms, by emphasising the other roles they continued to fulfil, such as mother, daughter, husband, and friend. This split between self-identity and body may have particular implications for people who ultimately have a 'difficult' death. By separating themselves from their bodies prior to death, by reasserting those identities which do not require the physical body *per se,* it may be easier for their loved ones to continue writing their 'last chapters' after their deaths.

Living and life

As this thesis is structured by respondents' accounts it seems appropriate in this final section to give some of the last words to them. Throughout I have discussed the ways in which respondents managed their dying within the context of their own lives. However, it is important to note that facing one's own mortality is hard. Dying is not straight forward. One does not drift through stages, ultimately reaching awareness and acceptance at the end. Although many respondents did indeed know they were dying and to some extent accepted that, at the same time they remained fearful and sad; they hoped that science would make that break through just in time for them. Anna's account below illustrates some of the mixed emotions respondents spoke of:

> I'm coming to the end, and I just can't believe it myself really. Waiting for a miracle I think.......I feel that the time's getting closer, and I suppose I'm accepting it better now because there is nothing on offer for me. It's not like somebody's come up to me and said, "We want to try this new treatment on you." There is nothing else. I only have to look in the mirror, I'm not a fool, I can see by myself that I'm getting thinner.

We are all dying. However, we do not define ourselves as such, we live our lives not die them. Equally then although respondents were aware that their cancer could become, or was terminal, they did not automatically define themselves as 'dying', but still clearly concentrated on the fact that they were 'living'. As Ann pointed out to me in many ways she was no different to me:

> But at the end of the day you're not much different to anybody else, I mean anybody could die tomorrow, you could probably die just as easily tomorrow as I could.

Respondents knew they were dying, but to them this was not their 'master status'. Although at times others seemed to treat them purely as one-dimensional terminally ill cancer patients, it was clear that they conceived of themselves as so much more than this. Respondents had a 'multiplicity of selves' (Goffman,1978), and their stories illustrate their multi-dimensional self-identities. As their physical capabilities decreased they did not necessarily cease to occupy particular roles, rather they modified and renegotiated them. Individuals made decisions which were meaningful within the contexts of their own lives, in order to keep control over their own

lives, and hence continue to maintain the roles and identities they held dear. Although all respondents were living with dying, this was only one part of their lives. However, this was the part which demanded the most emotional work, if their 'dying' status was to be prevented from 'taking over' their lives completely. Now as I finish this thesis, I am aware that when I began my research I thought this would be a study about dying and death, I now realise it is actually very much about living and life.

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