Living with cancer: understanding the experiences of close relatives of people with cancer.

Plant, Hilary Jane

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Living with Cancer

Understanding the Experiences of Close Relatives of People with Cancer

Hilary Plant

School of Education,
King’s College London

Submitted to the University of London for the degree of Doctor of Philosophy
ABSTRACT

This study describes the experiences of close family members of people diagnosed with a common cancer. The aim is, using qualitative methods, to look at how relatives live with the ongoing illness. Twenty six participants were interviewed up to three times in their own home. The tape recorded interviews were open but focused around the participants experiences since their close relative had been diagnosed with cancer. The research process was reflexive and aimed to be sensitive to the potentially distressing nature of these interviews. An inductive thematic approach to analysis was used. Three inter-linking dimensions of these experiences (existential, emotional and practical) were identified. The existential dimension describes the disruption of self identity and internal security experienced by the close relatives who often put the well-being of the person with cancer before their own. Expression of the participants’ own emotional distress was difficult and invariably suppressed. There were increased practical demands on these relatives but many of them found that the satisfaction of caring for the person with cancer helped them ‘cope’ with the situation. Contextual and social factors which influenced the dimensions and created differences in the experience included the relationship with the patient, life circumstances and gender.

The research has some implications for practice. It illustrates why the relatives’ ways of managing the illness, for example by protecting the person with cancer and minimising the threat of the illness, made many of them both ‘invisible’ to professional carers and marginalised from the support that the person with cancer received. An unexpected finding was the therapeutic nature of the research process which allowed participants to tell their own story, offering acknowledgement and an opportunity for reflection.
For those who could not stay
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ACKNOWLEDGEMENTS

First I would like to thank all those who took part in this study. They gave their time and thoughts so generously. I think about them often and wish them well. This thesis does not do justice to their experiences, but I at least will always take heed of their words in my practice in the future.

This work could not have been completed without the enormous support of several other particularly wonderful people.

I have been honoured to have Alan Cribb as my supervisor. He has helped me to think creatively about the issues raised by this project. I would have given up long ago if not for his patient support and gentle encouragement. I admire his intellect enormously, and now value his friendship even more.

My great friend Mary who has been with me as social, emotional and academic support all the way through; crying, laughing, bathing the girls. I hope we can now go out and have some fun!

My parents' love, encouragement and practical support is so much part of our lives that we never thank them enough. In particular, they looked after me daily when I was pregnant with Ella, crucial for both of us.

Without Jeremy and Ella of course I would not have finished this at all. Ella does not know life without the ‘Ph. D thingy’ but becomes increasingly creative in her ways of getting me to ‘hurry up’. Poor Jeremy has had a hard time, his amazing endurance and ability to still believe in me when I have been full of self-doubt is a serious achievement. His love and practical support have meant everything. **Thank you.**

There are many others who have helped me on my way. My friends and colleagues at the Centre for Cancer and Palliative Care studies have been lastingly supportive and
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Finally I would like to thank Cancer Relief Macmillan Fund for providing the initial funding which allowed me to undertake this work.
PREFACE
"Goodbye," said the fox. "And now here is my secret, a very simple secret: It is only with the heart that one can see rightly; what is essential is invisible to the eye."

"What is essential is invisible to the eye," the little prince repeated, so that he would be sure to remember.

"It is the time you have wasted for your rose that makes your rose so important."

"It is the time I have wasted for my rose - " said the little prince, so that he would be sure to remember." (Saint-Exupery 1974)

This thesis has taken a long time to evolve. It began by chance with a newspaper advertisement for a Ph.D. studentship as I was completing a degree in history at the London School of Economics. This offered an opportunity to build on my earlier research experience as a cancer nurse and so seemed enticing. When I started I felt enthusiastic, free and with a relatively uncluttered life. As I write this, eight years after the advertisement, my five year old daughter, Ella, is sitting on the arm of my chair and telling me that I am being boring - she leaves me to go to 'catch my prince'.

Much change has taken place during the time of writing the thesis - social, cultural, political, academic and personal. Indeed, in many crucial ways the world is already a different place from when the first interviews in the study took place in 1991. Nevertheless, I do not believe that this makes the participants' words out of date - rather, this has enriched my reflections on them. Throughout the thesis I have attempted to indicate some of the implications of these changes.

In particular, notions of family are currently shifting so that one almost becomes wary of using the word 'family'. Definitions may vary (Muncie and Sapsford 1995; McClement and Woodgate 1998) and an individual's concept of whom they perceive as their family covers a very wide range of relationships and ways of living. One of my daughter's favourite television programmes was 'Sesame Street' (based in New York, for under fives and very 'politically correct'). A song which we both enjoyed was called 'We are a family' and depicts the wide variety of relationships which in 1999 constitute a 'family', for example, families which incorporate sets of divorced parents, single parent
families, same sex couples. Ella is in tune with the relationships that the song describes - but she is of a different generation from those who took part in this research, the majority of whom are over 60 and married. It is these latter types of relationships this study mainly describes. This might seem insensitive to what is happening in our society. Nevertheless, what is enduring is that in a multiplicity of different ways people do have relationships - and many of them are long term.

A major influence upon this study are my experiences as a nurse, my discussions with nurse colleagues and with my partner who is a cancer physician. This work has drawn upon many disciplines but in the end it is written from the viewpoint of a nurse. I have been registered within a department of education, which has been both liberating in that I have had no pressure to follow a particular school of thought or style, and isolating, so that with the great exception of my supervisor, most of my support systems have been from outside the university.

I have come to this research by several routes. A crucial personal motivation was provided fifteen years ago by my first research post on the oncology unit at the Homerton Hospital in east London. This provided me with an initial research training and also the desire for the qualification to run my own research projects. The experience also provided the basis for much of my thinking about this research. I felt uncertain about the large numbers of quality of life questionnaires I administered during this period, never really believing that these forms gave adequate representation of the patient’s experience, and feeling the injustice of asking people to fill in questionnaires without attempting to address the issues raised by them. Nevertheless, I also had time to be with patients and work in more creative ways than I had hitherto been able; setting up and running weekend seminars for cancer patients and those close to them (Kfir and Slevin 1991), establishing an art therapy group and a monthly out-patient support group. The comment made by the wife of a patient used to introduce our paper about the support group illustrates the thread that led me to this current research:
"The group has made me realise that it is all right for me to feel anguish and frustration just as my husband does. Until now it has felt as though both of us have the cancer, but only one is being treated for it.” (Plant et al. 1987)

There has been a shift since the inception of this study towards the gradual acceptance that qualitative methodologies could be usefully applied to healthcare research. When I first started such methods were regarded as unorthodox. Remarkable then, that a paper discussing the information needs of cancer patients which used similar methods to those used in this study has been published recently in the British Medical Journal (Leydon et al. 2000).

When I first registered for this research degree I was working part time at BACUP, a national information service for patients with cancer and their families. It was the relatives of cancer patients who were the predominant users of the service (Slevin et al. 1988). Telephone calls from the family were typically about complex issues, yet often what the caller really wanted was to be able to talk this through and be listened to in a non-judgmental way. The information required was sometimes about areas which the caller found difficult to talk about elsewhere, such as discussing what actually happens when someone dies.

Most of the time that I have been working on this thesis I have been employed as a part time lecturer at the Centre for Cancer and Palliative Care studies at the Institute of Cancer Research and the Royal Marsden Hospital in London. Here I have been involved with setting up, running and evaluating a clinic for people with lung cancer who are breathless (Corner et al. 1995; Corner et al. 1996; Bredin et al. 1999). A recurrent and difficult issue raised by many who have taken part in this research is how we should best address the needs of the partners and close family of the people who come to our clinic.

The research has also been set against other more personal experiences. During the first couple of years of the research I spent much time with my great friend Anne Dennison who died from ovarian cancer in 1992. At the time this was a central focus to my life and made working on the project very difficult. Nevertheless, it also became part of the
work: I piloted an early interview with Anne and rehearsed my first conference paper with her husband Paul with whom I have continuing discussions. Since then several relatives of friends have been diagnosed with cancer, and I have frequently felt thrown into my own work - feeling that the process of this research has enabled me to support them better, and sometimes feeling guilty that their experience affirmed the research findings. Whilst undertaking this project I myself have also experienced the sadness and loss of six miscarriages as well as the birth of a very premature baby. I now know the reason for this is that I have a chronic, non life-threatening disease, the implications of which are still unclear, and yet which in my view remains more of a taboo than cancer. This has undoubtedly coloured the way I look at things.

Finally, from the start of my deliberations about this project, I have been preoccupied with the tension between the academic voice and the voices and experiences of individuals. From both a personal and a professional perspective I have been dissatisfied with the mismatch between much of the academic ‘jargon’ and the raw, and sometimes inexpressible, reality. My primary desire has been to understand these experiences and to help others to understand them – not necessarily to explain them or change them (although with hindsight I hope I have made a small contribution to this too). In writing this dissertation therefore I have in many places and respects tried to stick close to the experiences and language of the research participants. However at the same time I have sought to learn from a range of academic work and bring its strength to bear on this task.
Chapter 1
CANCER: SOME RELEVANT BACKGROUND
INFORMATION
This study is about the experiences of the family and friends of people diagnosed with certain common cancers. The aim is to look at how individual relatives live with the ongoing illness and how their experience might change over time. The focus of the research is on life at home. This is not primarily a study about caring, although this is naturally integral to the experience for many. It also does not intend to deal closely with death or bereavement - although this inevitably becomes a part of the story for some families.

'Family' is a difficult notion to define and will have a different meaning for each individual according to their personal experience. The focus here is on the defining relationships in a person's life; that is those with whom there is a degree of emotional attachment, however complex this might be. Thus the terms 'family' or 'relatives' are used to refer to those who are close to a person who has been diagnosed with cancer and includes partners, offspring, siblings and close friends.

As this study is focused around the experiences of those close to someone with cancer, the person with cancer obviously figures highly in this thesis. The word 'patient' is now less generally used in sociological and nursing papers to refer to a sick person because of its paternalistic and institutional overtones. Respect for the individual is central to this work, nevertheless the word 'patient' remains in everyday use and the aim here is to reflect real life. The word 'patient' is also used in older academic and medical papers, and furthermore can sometimes provide clarity to a convoluted sentence. It will thus, with no disrespect intended, occasionally appear below.

CANCER

Cancer is the cause of a quarter of all deaths in the UK (Office for National Statistics 1997). Lung cancer is the commonest cancer in the UK, with 40,000 new cases diagnosed each year, and around 37,000 deaths (Cancer Research Campaign 1996). Bowel cancer is second to lung cancer with 28,000 new cases of the disease occurring annually and 19,000 deaths (Cancer Research Campaign 1993). These two sites of
disease were chosen for this study because of their frequent occurrence and also because of the relative paucity of research into the social and emotional experience of the families of patients with these cancers (compared with for example, breast cancer or the families of children with cancer). Three participants referred to the research had genito-urinary cancers which are less common.

Nearly half of all newly diagnosed cancer patients will survive for more than 5 years. Living with this illness is thus a relatively common experience for both people with cancer and their families and friends. Different disease sites and stages provoke different experiences. Many of the studies which look at the effects of cancer (with the exception of breast cancer) include several different disease sites - this current study is no exception. The participants’ accounts have not been analysed by disease site but it is hoped that enough context will be provided to illustrate the differences as well as the similarities in experience.

**Lung cancer**

The incidence of lung cancer is strongly related to age, it is uncommon under the age of 45 years but remains the most prevalent form of cancer in men over 65 years. While the overall trend is a reduction in lung cancer mortality, death from lung cancer in women is rising. There is an incontrovertible aetiological link to cigarette smoking (around 80%). Approximately 80% of adult smokers start smoking as teenagers. Smoking is the greatest single cause of preventable mortality in the U.K. (Standing Medical Advisory Committee 1994).

Many of the symptoms of lung cancer, for example cough, shortness of breath, feeling generally unwell with a loss of appetite, may be common long standing problems for many people who smoke (Krishnasamy 1997). Other symptoms include pain and coughing up blood (haemoptysis). Diagnosis of lung cancer is by chest X ray and usually fibre optic bronchoscopy. The prognosis is poor with less than 10% of patients alive 5 years after diagnosis. The most effective form of treatment for lung cancer is surgery but unfortunately in most people the disease is too advanced by the time of
diagnosis for this option to be feasible. Palliative radiotherapy and chemotherapy may be given to relieve symptoms but invariably this is of short lived benefit (Souhami and Tobias 1995).

Lung cancer is perceived as a ‘low priority’ cancer (Pickles 1997). There is no vocal lung cancer lobby, and much of the interest in lung cancer lies in ways of preventing the disease. Thus, the resources for the support of those with lung cancer who need individual and sensitive continuity of care and symptom management are less forthcoming than for other cancer sites (Pickles 1997).

A recent national needs assessment study of patients’, families’ and professionals’ perceptions of need in lung cancer found that people with lung cancer delay presenting to their GP despite experiencing debilitating symptoms. Entry into the hospital system was then further delayed by the GP for a significant proportion of people and follow up care for patients having completed their hospital treatment was inadequately recorded. Patients described living with multiple problems such as breathlessness, pain, fatigue, anxiety and depression, with little help available in the community. However, despite the majority of patients identifying themselves as being dependent on family and friends since diagnosis, only about half the patients believed that lay carers themselves had unique needs arising from their caring role (Krishnasamy 1997).

**Bowel cancer**

Bowel cancer is also a disease which occurs predominantly in those over 60 years and has a relatively low public profile. There is evidence for a link between diet and colorectal cancer with the disease being uncommon in Africa, Asia and South America - the low residue Western diet leading to a higher exposure to any carcinogen passing down the alimentary canal than the ‘rapid stool transit time’ of the African diet (Souhami and Tobias 1995, p.307). People experiencing symptoms such as a change in bowel habit, pain on defecation or blood in the stool may delay seeing their GP. Indeed some people may experience few symptoms at all making early diagnosis difficult. However, there is
some evidence that there is an improving trend towards earlier referral for consultation by GPs (NHS Executive 1997).

Diagnosis of bowel cancer is by sigmoidoscopy, colonoscopy or barium enema. The prognosis is dependent on the extent of the disease with well localised tumours carrying a high probability of surgical cure. Nevertheless over half of large bowel cancers ultimately prove fatal (Souhami and Tobias 1995). Surgery is the cornerstone of treatment with some patients benefiting from adjuvant radiotherapy or chemotherapy. Chemotherapy may be used in recurrent and advanced disease.

There is debate over the strategy for follow up of patients after initial treatment with practice ranging from every three months to yearly or never. Follow up include clinical examination, colonoscopy, barium enema, sigmoidoscopy, scans and blood tests, but the value of these tests in follow up is still unclear (NHS Executive 1997).

Surgical cure may leave some patients with a permanent colostomy. Here the skilled support of a stoma therapist for both patient and family is essential to ensure the well-being of both the patient and their family (Souhami and Tobias 1995). Symptoms of recurrent disease may include pain, anorexia and fatigue. Early referral to specialist palliative care has been found to improve emotional and physical symptoms of the illness and both patient and family satisfaction (NHS Executive 1997).

*Genito-urinary cancer*

Cancer of the kidney, bladder, prostate and testis represent over a quarter of all cancers in males. These tumours can be difficult to manage although surgery has traditionally been the cornerstone of treatment (Souhami and Tobias 1995). Testicular cancer is exceptionally responsive to chemotherapy with a very high cure rate even when the disease is disseminated. Nevertheless as this is most commonly a disease of young men its occurrence may cause great distress (Souhami and Tobias 1995). Surgery for bladder cancer may again involve the formation of a stoma with the inherent need for sensitive practical information and support.
THE CHANGING CULTURE OF CANCER CARE

The last three decades have witnessed a change, both in terms of what is provided by the professional carers of people with cancer and what is expected by the patient and their family. An openness about the diagnosis and its ramifications is now the starting point for working with cancer patients and there is an expectation that professionals in cancer care should have the training and aptitude to deal with the emotional sequelae of the illness. For the patient and their family there is a much greater awareness of the disease and expectation of treatment. Stories of individuals’ experiences of cancer can be followed on the television and in the newspapers bringing close personal insights into a set of experiences which many now believe should be openly discussed. Furthermore, there is a plethora of information to be obtained via media coverage of miraculous treatments for cancer, for example with ‘magic bullets’, and the use of the internet to obtain detailed information about disease and its treatment (Kelly and Field 1998) – although this in turn may create an unrealistic anticipation of what might be provided.

Wellisch (1998) believes that, as much has altered over the last 25 years in cancer care, there is now ‘the recognition that cancer is an emotional crisis for the entire family unit’ (Wellisch 1998, p.1). It is unlikely that anyone would argue with this. And yet the literature about how to support this emotional crisis is inconclusive, and details about what this experience is for the individual family members themselves remains scanty.
Chapter 2

CANCER AND THE FAMILY: LEARNING FROM OTHER WORK IN THE FIELD
INTRODUCTION

This chapter is an overview of those papers and books which illuminated my thinking during the research about the experiences of those close to someone diagnosed with cancer. In this chapter I have deliberately not discussed all of the literature found in my original (very broad) literature review. Rather I decided to only include literature in proportion to its relevance to my own study. This obviously entailed looking at all of the literature and reading most of it, but in so doing it became clear that much of it — either because of its focus or methodological style — had little bearing on my concerns. To borrow the term from data analysis I went through a process of 'progressive focussing' through which I gradually increased the attention I paid to some studies whilst reducing the time spent on others. Indeed — as I have made clear elsewhere — the data analysis and literature reviewing developed together and interactively, and the progressive focussing resulted directly from these interactions between reading data and other literature. What I have included is here for everyone to see. It may be helpful if I also make explicit the main categories of research which although addressing family issues have not been fully included because they did not profitably inform the understanding the experience of the relatives of adults with newly diagnosed cancer involved with this study. These relate to work in the areas of: bereavement, childhood cancers, breast cancer, haematological cancers, carers and several of the studies which attempted to measure or quantify the experience - particularly the distress - of the family of people with cancer.

Thus the literature which is included both in this chapter and throughout the dissertation is cited because of its relevance to the development and findings of the research. It also indicates the reasons for choosing to undertake this study.

This review commences by further 'setting the scene', beginning with some of the issues concerning the professional carers. Although this study did not involve interviews with health professionals they are an important backdrop against which the relative’s experience takes place. Furthermore, they are the most likely audience for this work.
Second, there is a consideration of the societal view of cancer, illustrating how cancer may be different from other chronic illnesses. As much of the research on the psychological and social impact of cancer uses quantitative research methods it was important at an early stage of the review to elaborate some of the reasons why these have not been used for this study, particularly as this decision informs the way the literature described later has been chosen and discussed.

A section on the family and the impact of cancer forms the bulk of this chapter. This examines the experience of the family from a variety of perspectives, attempting to create a picture against which the findings of this research may be contrasted and compared. It begins by addressing some of the current theoretical perspectives on the family and the importance of close relationships for the individual. It is usually anticipated that those close to someone diagnosed with cancer will provide care and social support. This is often seen from the patients perspective, rather than for what this might mean for their relatives.

Cancer engenders difficult emotional and physical symptoms in those close to the patient as well as in the patient themselves. The research looking at these issues as well as how the professional carers might support the relatives is described next. This section finishes by examining other qualitative studies looking at the experiences of those close to someone diagnosed with cancer.

The chapter concludes with a brief comment about the published illness stories which provide further helpful insight.

To avoid excessive repetition cross reference has been made when a paper or book provides illumination in more than one place, so some of the studies mentioned in this chapter will be elaborated in more detail later in the thesis.
EMOTIONAL CARE AND DAY-TO-DAY PRACTICE

Despite the open discussion about cancer and death in the media and the academic press, the countless papers on the benefits of open communication, continuity of care and psychological support, there is still considerable evidence that patients and their families are not receiving help that meets their needs (Krishnasamy and Wilkie 1999). This gap between theory and practice may be for several reasons.

It may be that despite the increased acknowledgement of the potential social and emotional needs of the patient and their family, the professionals themselves may be unable to put this knowledge into practice. The care given by professionals may be governed by tradition and routine, and follow ritualistic patterns rather than rational action (Carter 1996). Carter (1996) suggests that this may be because the use of obscure jargon and complicated research strategies often seen in research reports do not seem relevant to every day patient care. Involvement of the professionals themselves in the research process is one possible way to avoid this (Meyer 1993). However, Carter also suggests that many of the theories and traditions underlying nursing practice which prevent making time for different ways of working may in fact protect nurses from stress. Menzies Lyth's seminal study from 1959, reprinted in 1988, (Menzies Lyth 1988) which considered the high level of stress and anxiety chronic amongst nurses in a general hospital still seems in several ways relevant today.

Menzies Lyth examined the functioning of the social systems (of the hospital) as a defence against anxiety. Writing from a psychoanalytic perspective Menzies Lyth described the high levels of tension among nurses and the consequent withdrawal from duty. She believed that the relationships with patients may create anxiety, doubt and guilt in junior nurses which was managed through the development of an institutional 'social defence system' (p.51). This, for example, operated by constantly moving the junior nurses and organising their work such that there was little time to create a relationship with any one patient - thus eliminating the potential satisfaction of care that the nurses initially entered their profession for. Ritual task performance may also
eliminate the worry of decision making and a hierarchical structure of working prevents
creative thinking from those working most closely with patients, and acts as a barrier to
cchange. Menzies Lyth wrote four decades ago and it may be argued that things have
changed since then. Nevertheless, her findings certainly applied to my own training
(two decades ago) when I have often described myself as being 'unable to think' during
my three years as a student nurse. Now with 'patient centred care' and 'named nurses',
a continuity of relationship with the patient should be central to nursing care. But, from
listening to patients and my own observation in clinical and other settings it seems that
there still remain many barriers for nurses in reaching their own independent, creative
and therapeutic potential in working with patients and their families.

Savage's (1995) ethnographic study explored the notion of 'closeness' between the
nurse and patient found that experienced nurses understood this closeness as 'form of
rapport which allows self-disclosure or 'openness'' (p.3). 'Closeness' developed where
nurses were well supported which meant to them among other things, adequate staffing,
stable workforce and appropriate training. When pressure on resources meant staff
shortages and lack of endorsement from managers and medical colleagues, nurses
became more stressed and were unable to sustain the 'close' relationships they had
previously established with patients (Savage 1995).

Corner (1990) found that the predominant cause for concern of newly registered general
nurses questioned about their experience of cancer care was that of communicating with
patients and their relatives. Corner quotes an extract from an interview with a nurse
which illustrates the effect the experience appeared to have on the nurses and also the
apparent lack of support for them in dealing with this:

*Nurse:* “There was a lady, she had cancer of the lung and they operated and
it was no good. And she was sort of going downhill.... I used to love her, I
thought she was gorgeous but we never really talked in depth about her
condition and then she said to me ... ‘Am I going to get better?’ and I just
looked at her and I couldn’t have the heart to turn round to her and say ‘Well
no you’re not’ and I didn’t know how to tell her that she was, or if it was my
place to tell her.”
Researcher: "So what did you do?"
Nurse: "I can't really describe it you know, you just waffle your way through it and sort of avoid the question totally."
Researcher: "Then what happened?"
Nurse: "Well then I found it really hard to talk to her after that, I had to avoid her because I couldn't ... I felt so guilty not being able to help her when she put so much trust in me by asking a question like that and I just couldn't help her."
Researcher: "That must have been horrible."
Nurse: "...I don't know if it effects you in a way you don't realise its affecting you. When I went home that night I cried, I really cried because I just couldn't help her."
(Corner 1990, p.176)

Lanceley has studied the implications for cancer nurses of talking with patients and accepting their feelings and distress. Her findings suggest that responding to cancer patients has consequences for the nurse's own identity and self image (Lanceley 1997). Smith (1992) describes how nurses must suppress their own feelings in order to make others feel cared for. She comments that nurses may develop strategies to deal with this, some of which are positive but also many which are evolved 'to protect them from a range of feelings: guilt, fear, failure and anger to name but a few' (Smith 1992, p.15).

Cancer and death are difficult to talk about - this obviously applies not only to the professionals but even more so to the people with cancer and their families. Furthermore, the patient and their family may not want the help and support of someone perceived as a stranger. This research was associated with a project aiming to look at cancer patient's perceptions of need and relief in the first year after diagnosis. Underpinning this study was a belief that there may be a mismatch between what the person with cancer wants and what the professionals perceive the patient might want (Bliss and Johnson 1995). A randomised controlled trial of adjuvant psychological therapy (a cognitive and behavioural treatment) for men diagnosed with testicular cancer found that there was no evidence of benefit observed in the group which received treatment (Moynihan et al. 1998). However, the majority of men (60%) who were asked to participate in the trial refused. Discussing the findings where men with testicular cancer were found to have 'considerable coping abilities', the authors of this study raise
a note of caution that the creation of a counselling role within a healthcare team may cause a split between the care of the mind and the body. Thus professionals may feel that the duties of informing and reassuring patients should be passed to a counsellor, whereas in reality the task may be undertaken more therapeutically by a clinician concerned with all aspects of their care.

Furthermore, a recent study undertaken by St Christopher's Hospice in London, which looked at factors which influence where people die, found that there were many occasions where offers of help from community nurses were refused by the relatives, despite being under considerable stress (Armes and Addington-Hall 2000). It is hoped that by providing some further understanding of the relatives' experiences from their own point of view, this study may give some insight about why these people might find accepting support from the professionals difficult.

FEAR AND STIGMA ASSOCIATED WITH CANCER

Cancer is still perceived as being different from other illnesses. In a society which cherishes health and longevity, a person with cancer has a potentially life threatening illness whose progression and treatment may cause loss of physical and emotional well-being.

Mathieson and Stam (1995), interviewing people with cancer in Canada found that all but two of the 37 who participated in their study spontaneously mentioned issues related to the stigma of cancer. They quote a woman who described her friend with cancer:

"I looked at her and I thought ... I couldn't think anything else of her, I couldn't think what a fabulous person she was, I mean, she had in capital letters, written from the top of her head to the bottom of her shoe, CANCER, and I couldn't get beyond that to see the person she was." (Mathieson and Stam 1995, p.297)

A large study of the stigma associated with rectal cancer in south London found that poor physical health was more highly correlated with feelings of stigma than having a
colostomy (Macdonald 1988). However, for those with a stoma, fear of exposure restricted many participants lives and was associated with reduced interest and participation with customary outside activities. In this study family were not interviewed to elicit their views on whether they themselves felt stigmatised by the patient’s illness. Goffman (1963) argued that those with a close relationship to the stigmatised person, ‘are all obliged to share some of the discredit of the stigmatised person to whom they are related’ (Goffman 1963, p.43). Goffman sees problems of being stigmatised by association as diminishing with the closeness of the relationship. This may cause connections to be either avoided or terminated. Goffman also points out that those stigmatised by association may suffer the deprivations but be unable to enjoy some of the possible benefits experienced by the stigmatised.

Cancer is commonly used as a metaphor for something which is evil, harmful or uncontrollable, a metaphor for corruption and deviance. It is used by politicians, sports commentators, daily newspapers and in general conversation. Despite an increasing openness in talking about cancer and the existence of a larger group of survivors from the disease, this powerful image does not show any signs of going away. This may be regarded as offensive to people who have cancer, nevertheless Seaton, writing about his wife’s breast cancer comments:

“Small wonder cancer has held so much appeal to writers and poets as a metaphor for social corrosion and political alienation: it goes about its grim business on many levels. In the last few weeks, when the cancer was rapidly advancing towards the ultimate Pyrrhic victory of killing its host, I often felt that, as Ruth was dying, our relationship was by degrees dying with her.”

(Seaton 1998, p.103)

Sontag’s (1977) seminal work addressing illness and metaphor draws out the metaphoric associations between cancer and warfare. Notions of treatment are brutal, thus it is aimed at ‘winning the battle’ against cancer and fighting the disease. As Sontag points out surgery is ‘radical’, radiotherapy ‘bombards’ the tumour and chemotherapy aims to ‘kill’ the cancer cells leaving the body with little ‘defence’ (Sontag 1977). Even as I write, a new series entitled ‘Cancer Wars’ is advertised on the television. Sontag calls
for a resistance to metaphorical thinking and yet currently these metaphors have if anything been extended. Corner illuminates how these may be examined further in the context of the ways health care professionals think about cancer (Corner 1996).

Survival is the focus of cancer management. Corner (1997) points out how this 'culture of war' influences the ways in which cancer is discussed with those who have it, 'since winning the battle justifies heavy casualties and the risk of wounding' (Corner 1997, p.176). The fear of cancer is such that patients are willing to undergo toxic treatment with only a very small chance of cure. In a study which aimed to compare how people assessed their personal cost-benefit equation for chemotherapy it was found that there were large differences in the responses of patients who actually had cancer and a matched control group (Slevin et al. 1990). The majority of patients (53%) when faced with a hypothetical situation involving very intensive chemotherapy with severe side effects would want to have the treatment with only a 1% chance of cure, whereas in the general population less than 20% said they would undergo such treatment. When faced with a diagnosis of cancer it seems people are so frightened that they are willing to take long odds and endure great suffering for potentially little reward. Even the fear of AIDS has not supplanted the fear of cancer in the public conscience perhaps because there is clear knowledge about the avoidance of the risk of AIDS (Winstanley Douglas and Partners 1988).

On the other hand a diagnosis of cancer will elicit sympathy and people do give generously to cancer charities. A few years ago an Imperial Cancer Research Fund advertising campaign showed a photograph of a woman named Stella Tilson quoted as saying: 'The fight against cancer isn't hopeless and I'm living proof of it'. At a local billboard in Hackney, this and other posters were almost completely obliterated by fliers for a left wing radical political group. Nevertheless, the photograph of Stella Tilson herself stood out, remaining unsullied and it seemed at the time to indicate that anything in society may be kicked against - except someone who had cancer.
MEASUREMENT OF THE PSYCHOLOGICAL AND SOCIAL IMPACT OF CANCER

When at the time the study commenced, I chose to use qualitative methods for this research, these were less commonly used in health care settings than at the time of completing the project. However, as a more positivist approach remains the preferred method for the majority who work in psycho-social oncology and as much of the work about those close to a person with cancer uses these methods, some of the relevant papers are included here. The inclusion of these studies is also used to illustrate why I considered quantitative methods inappropriate for my own project. When planning to survey a large population about their response to a situation it is obviously not possible to conduct an in-depth interview study. In order to look at individual meaning and the contributing factors behind particular sets of circumstances a qualitative approach is more helpful.

Cull (1991) looked at stress in carers of cancer patients, both lay and professional. She believes this stress occurs when the perceived demands of the situation exceed the individual’s resources to meet them. Cull (1991) poses the question, ‘Studying stress in care givers: art or science?’ And she concludes:

"The application of rigorous scientific methodology to these problems offers the only means of elucidating the stress processes and evaluating interventions to relieve the stress of caring for cancer patients." (Cull 1991, p.983)

Cassileth and colleagues (1985) included the family in their psychological analysis of cancer patients and their next of kin because of concern about the family’s ‘ability to fulfil the patient’s needs’ (Cassileth, 1985, p.72). This study applied self-report tests of anxiety, mood disturbance and mental health to 201 cancer patients and their relatives (the Spielberger State Anxiety Scale, the Profile of Mood States and the Mental Health Index). This ‘battery’ (p.73) of tests took approximately 45 minutes to complete and found that patients’ and relatives’ scores for each of the psychological tests was
significantly correlated with an overall emotional stability in the participants - a similar degree to that reported for the general public (Cassileth et al. 1985).

Kissane and colleagues (1994) studied 102 families of patients with cancer to investigate their psychological morbidity (Kissane et al. 1994). This research used different tools and found that;

'Beck Depression Inventory-derived caseness was identified in one half of patients, one-third of spouses and one quarter of offspring, suggesting that psychological distress reverberates substantially throughout the nuclear family' (Kissane et al, 1994).

The study by Kissane et al (1994) also failed to find any close association between the psychological distress of patients and family members. Nevertheless, explanations for this as well as the high level of distress found in the family are only conjecture as the results are presented as an aggregate and there are no details of the context or family circumstance engendering these reactions. A further longitudinal study using psychometric tests to examine psychological adaption among the family of patients with cancer (Ell et al. 1988) also found that a substantial minority of significant others experienced psychological distress up to one year after the diagnosis. Here, however, the tests taken together indicate that the individual personal and social resources of the relative, rather than the patient’s physical condition are primary factors in declining mental health for the family. This contrasts with Cassileth et al, (1985) who found psychological well-being worsened according to whether patients were receiving follow-up care, active treatment, or palliative therapy.

Quinn et al (1986) using ‘good quantitative research’, (p.81) studied lung cancer patients and their partners to investigate how the support of the spouse and the patient’s own coping strategies mediated the patient’s psychological reaction to their diagnosis - finding that indeed patients who received more support reported decreased distress (Quinn et al. 1986). This study is again centred on the well being of the patient although the discussion focuses on the suffering of the family. The authors comment that they
experienced difficulties during this study with the professional carers who perceived that the research could be 'emotionally devastating' (p. 88) for the participants. Nevertheless the researchers observed that many of the patients and particularly the wives welcomed the opportunity to talk with someone about the illness (Quinn et al, 1986).

The family of women with breast cancer have been researched more than the relatives of patients with other cancer sites (Maguire 1981; Baider and Kaplan De-Nour 1984; Northouse and Northouse 1987; Hilton, 1993; Wellish, 1996). Northouse and colleagues (1998) planned a comprehensive comparison of couples' stress and adjustment to benign and malignant breast disease (Northouse et al, 1998). In this study multiple instruments with reported reliability were used to measure adjustment. To illustrate without elaborating, these were: Smilkstein Stress Scale, Dyadic Adjustment Scale, Family APGAR, Social Support Questionnaire, Mishel Uncertainty in Illness Scale, Beck Hopelessness Scale, Brief Symptom Inventory, and Psycho-social Adjustment to Illness Scale. The study found that couples in the group with malignant disease reported significantly higher levels of emotional distress and more role problems persisting over time than those in the benign group. In this study there was a high degree of correspondence between the adjustment of women and their husbands to breast cancer and, given the dropping off of social support, the authors recommend clinical interventions to support both over the first 60 days after diagnosis. No difference was found in levels of hopelessness between the groups which the paper postulates may be because couples with malignant disease may be unwilling to acknowledge their negative emotions, and as Northouse and colleagues point out, although the measurements were not different, in fact the underlying experience may not be the same.

The increasing acknowledgement of the distress which cancer may cause has been accompanied by a requirement to measure the incidence of these problems using instruments which have been validated for the task. Furthermore, testing the efficacy of new cancer treatments now frequently includes measurements to look at what impact the therapy has on patients' quality of life. Nevertheless, confusion still remains about how
best to measure this (Muldoon et al. 1998). Indeed, the translation of a persons’ emotions or quality of life into a number on a computer program in order to elicit statistical significance has so far done little to alleviate the individual’s distress, and apparently little to change the wider context of care (cf. Corner, 1997). Over the last two decades this activity of classifying the psycho-social difficulties of people with cancer has rarely addressed what these changes actually mean to the patient (Mathieson and Stam 1995).

Reviewing a large population may reveal generalisable trends in the distress caused by cancer to patients and their families. Nevertheless, as Klienman (1988) writes, for human suffering there is:

"no routine way of recording this most thickly human dimension of patients’ and families’ stories of experiencing illness. Symptom scales and survey questionnaires and behavioural checklists quantify functional impairment and disability, rendering quality of life fungible. Yet about suffering they are silent. The thinned-out image of patients and families that perforce must emerge from such research is scientifically replicable but ontologically invalid; it has statistical, not epistemological, significance; it is a dangerous distortion.” (Klienman 1988, p.28)

The studies cited above highlight the issue of the family of the cancer patient and indicate that the whole family is affected by a diagnosis of cancer. Aspects of the findings of some of these studies coincide with the experiences expressed by participants in this research and thus the two may be used to complement each other and where relevant these have been utilised in the findings chapters.

Many studies use mixed methods, both quantitative and qualitative - although ‘semi-structured interview’ may cover a whole variety of different research methods which often are not detailed. For example, the work of Oberst and colleagues (Oberst and James 1985; Oberst and Scott 1988) provides an overview of the distress for the relatives of cancer patients treated by surgery. This is a longitudinal study with patients and their partners contacted before discharge and at 10, 30, 60, 90, and 180 days post discharge. The research utilised standardised self report measures as well as a
‘relatively unstructured interview’ (Oberst and James, 1985, p.48). Oberst and James (1985) comment that the interviews provided the richest source of data and find that learning to live with someone else’s cancer can be very difficult ‘precisely because no one recognises just how hard it really is’ (Oberst and James, 1985, p.56). One spouse is quoted as saying;

“He has the cancer - I'm not sick, so I'm not allowed to have a bad day.” (Oberst and James, 1985, p.52).

Nevertheless, the measurement instruments also provided potentially helpful information (Oberst and Scott, 1988). Whilst the partner’s anxiety was high during the patient’s hospitalisation it came down immediately after discharge, perhaps because the partners felt more in control and able to take on some of the caring duties themselves. However the spouses’ distress then increased about two months later and continued at a higher level than normal. The authors postulate that this may be because of the patient’s continued egocentricity. In this study, as in that of Cassileth et al (1985) there were few differences in the intensity of distress experienced between the patients and their spouses. Moynihan and colleagues (1988) in the UK used both the Present State Examination and a specially designed semi-structured questionnaire to look at the psychological and social impact of testicular cancer on patients and those close to them. These authors were surprised at the significantly high levels of morbidity in the relatives and friends who took part in the study and postulate that the relatives’ overwhelmingly expressed desire for formal support may have been a reflection of their need to talk through their anxieties which were unmet elsewhere (Moynihan et al. 1988).

Evaluating new therapeutic interventions in the care of patients with cancer and their families is a crucial, but complex and difficult task. Here the ability to make comparisons of scores across populations is important in order to show that one treatment is better than the next. I have been involved with a multi-centre evaluation of a nursing clinic for breathlessness in lung cancer which used several instruments previously validated with cancer patients to measure the effectiveness of the intervention. The trial had a positive outcome, and yet the researchers involved felt that
the tools used were less than satisfactory - both in terms of their sensitivity to individual change and the impact that they had on the participants. One of the nurse researchers who took part in running a clinic commented:

"one [question] that stands out in my mind is, 'do you have despondent feelings about the future?' That was what really bothered him and made him think about the fact that he had lung cancer and wasn't going to be cured.... when we got to the visual analogue scale he actually couldn't put pen to paper... he was quite distressed." (Plant et al. in press)

The difficulties for the participant in completing these forms is rarely acknowledged. In a longitudinal study of the relationship between the psycho social response of the patient and care-giver burden, the sample of patient and carers was reduced from 103 to 31 (McCorkle et al. 1993). The main reason for this attrition was patient mortality followed by difficulties with the research instrument:

"many patients were unable to complete the full battery of instruments due to their debilitating conditions" (McCorkle et al, 1993, p. 25)

Using psychometric testing to estimate a patient's well being is certainly 'safer' for the professional who does not want any emotional involvement with their client at all. Here the author of a popular quality of life measure expresses his sentiment:

"I maintain that indices can be designed so that clinicians can score the patients quality of life or health status after observing or examining a patient even without eliciting information from the patient about he how or she feels at a given point in time." (Spitzer 1987) Quote taken from James (1992, p.504)

For many professionals who care for people with cancer and their families the need to measure psychological and social dysfunction seems very removed from how they see their work with patients and what they might hope to achieve in this. Thus, although there is an extensive literature to investigate the emotions of both patient and family which provide some useful information, much of this confines itself to individual diseases such as breast cancer and furthermore to attempt to measure elements of the
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Conrad, writing in 1987, comments;

“Families are important as interpreters, caretakers, support systems, and buffers; chronic illness also can place difficult strains on and new burdens on family life. Given this, it is surprising that so few researchers on the experience of illness have specifically examined the family role.” (Conrad 1987, p.15)

Several authors have reviewed research papers on the impact of cancer on the family (Cassileth and Hamilton 1979; Northouse 1984; Lewis 1986; Sales 1991; Kristjanson and Ashcroft 1994). Northouse (1984) and, building on Northouse’s work, Sales (1991) both use stages of the illness to identify problems reported to be experienced by the family. This is with the belief that the stage of illness is the key variable in understanding the psychosocial impact of cancer (Sales, 1991). This is a useful way of organising the literature (which can feel very unwieldy) but can raise difficulties as not all cancers complete discrete phases, for instance the illness trajectory of lung cancer may be particularly difficult to divide up. Moreover, both Northouse (1984) and Sales (1991) place communication problems on the subject of death and feelings of loss in the terminal phase of the illness, but for many families these may well be a problem from when a diagnosis of cancer is first suspected. Using the stage of the patient’s illness is dependent upon the patient themself, rather than what may be happening in the relative’s own life and how the relative as an individual might react to the situation. Thus neither this review of the literature nor the analysis of the research data has been organised around the phases of the illness.

This section looks broadly at literature related to the impact of cancer on the family, providing background to reading the findings of the study. This commences by addressing some of the theoretical perspectives on family relationships and then
continues by examining what close relationships might mean to the individual. Social support and caring are two areas of research where those close to a person with cancer have received attention. The physical and emotional symptoms experienced by these people are then further addressed followed by the studies which look at the relationship between the family and the professional carers. This section finishes with a review of qualitative research studies about the families experience of cancer.

Many of the papers cited are from the United States (USA). There are obviously some cultural differences between the United Kingdom (UK) and the USA and where possible there is an emphasis on papers from the UK, but these are in the minority.

**Theoretical perspectives on the family**

Much of the theory about the family has been developed as a basis for family therapy, formulating the predictable or repetitive patterning of family dynamics (Carter and McGoldrick 1989; Dallos 1995). It is not the intention of this study to apply a particular family theory to understand the findings, indeed it is hoped that the data reveal their own patterns which in turn shape the thesis. Nevertheless these perspectives may contribute to the way that the data is perceived and thus create some useful comparisons.

The structures of family life have undergone a great deal of change and upheaval over the last 30 years. In its ideal form family provides a nurturing supportive environment from which to lead one’s daily life. The family is vulnerable to both the internal tensions created by close relationships and from the external pressures which may be taken home to process. Each family grouping is a unique and personal system. Some families are very private not wishing the outside world to know any of their business whilst others look more to outside resources to alleviate their difficulties. Families do not simply absorb current ideologies and discourses wholesale, but they translate them into their own family culture (Dallos, 1995).

The concept of the family life cycle (Carter and McGoldrick, 1989; Dallos, 1995) although limited by its rather normative view of family development looks at how
families move through various life stages from courtship to retirement and old age and face developmental tasks such as birth, marriages and deaths. The way families may deal with these life tasks is governed by family attitudes, taboos and expectations (Carter and McGoldrick, 1989). This model indicates that families need to adapt constantly to the tasks and stresses that face them, it takes a linear view of the problems which the family may encounter.

In contrast, systems theory (Dallos, 1995) suggests that families may attempt to create some stability and coherence to cope with the constant upheavals of life and thus attempt to decrease the need for constant adaption. Systems theory draws out the interdependence in family action and responses (Dallos, 1995). This may be explained by using the analogy of tapping one part of a mobile which then sets the rest in motion in an essentially familiar pattern. Likewise, family responses can become patterned in a repetitive way with each member responding in a predictable fashion. Much of this communication in the family takes place at the unconscious level. Systems theory is describing the current 'here and now', the unconscious constant sending and receiving of messages, rather than the psychoanalytic ideas of the unconscious which are shaped by childhood experiences and past interactions (Dallos, 1995).

Psychoanalytic understanding rests on the belief that there are several layers or strata to the human mind. Consciousness is our everyday awareness of our world around us. However some ideas, emotions and drives are deeper and unconscious, inaccessible from conscious thought. Psychoanalysts see the 'unconscious' comprising the powerful emotions and drives which are actively 'repressed' from conscious awareness in our everyday lives. The unconscious is thus the motivation for much of our action or reaction to people, events and situations (Wetherell 1995).

For example Minsky (1990) describes 'projection', one element of unconscious behaviour particularly relevant to this study, where people may be very anxious;
"We find a part of ourselves unacceptable (the thing we feel guilty about - our anxiety and insecurity, our vulnerability) and instead of allowing ourselves to consciously feel and acknowledge the feelings that we don't like, we project them onto other people and then feel under attack from these people". (Minsky 1990, p.4)

I have undoubtedly been influenced by some elements of psychoanalytic theory, not least, through undertaking a course looking at psycho-dynamic approaches to working with cancer patients at the Tavistock Centre in London whilst analysing the interviews. I have not attempted a psychoanalytic reading of the data. Indeed I have concentrated instead on taking what people have said at face value and, where I have done otherwise, have indicated so. This of course cannot take account of my own unconscious influences but the reflexive approach taken to the research process aims to make this as transparent as is possible (without being in therapy myself!).

**Marriage and close relationships**

Writing about close relationships, Rosenblatt and Wright (1984) describes marriage as a negotiation of shared views resting on what couples agree is important and true in their world. A couple may define their relationship through these shared views, for example, close, open, independent etc. Nevertheless there may well be some issues or areas which do not fit in well with this 'relationship reality'.

"A couple, for example, whose marriage reality includes a belief (reflecting societal standards and images of what relationships should be) that they are open with each other will have in the shadows the ways in which they are not open (the feelings, events and beliefs that each keeps from the other) and their awareness of withholding." (Rosenblatt and Wright, 1984, p.46)

A marriage reality may be that the partners are inseparable and will grow old together and always be there for each other (Rosenblatt and Wright 1984). Cancer will pose a serious threat to this. However, it may be that the couple will strain to retain their mutual vision of life together. To let go might feel like they were losing control or losing the balance of their lives. Thus, particularly if a couple believe they are open with one another, this 'shadow reality' of the illness may be present in the relationship,
with its implications never fully explored, and at great cost in energy and effort to the couple themselves and ultimately some avoidance of communication.

Murphy (1987) writes in a chapter entitled, 'The damaged self', about what it is like for him to be quadriplegic and the changes that this has forced on him - not just physically but socially and psychically as well. A tumour caused him to lose the function in all his limbs and Murphy describes his feelings of disembodiment where he has lost his sense of his own body from which he has also become emotionally detached. (Murphy 1987). Murphy comments ‘I had lost a part of myself’ (p.74), and he continues on to say how the illness had threatened everything that he and his wife had put together over the years. Murphy’s partner, Yolanda, may well have felt that she had lost a part of herself as well. Taylor (1991) writes, ‘The genesis of the human mind is in this sense not ‘monological’, not something each accomplishes on his or her own, but dialogical’ (Taylor 1991, p.33). Taylor comments that of course humans each develop their own individual opinions but, in important areas such as the definition of our identity, we define this always in dialogue and in struggle with our significant others. The people we love are essential to our internal identity throughout life. Thus if the person we love is damaged then we ourselves will also become damaged. Murphy, (1987) quoting Goffman, writes of his ‘spoiled identity’. It is impossible to imagine that his wife’s identity had not also been disrupted by the process of his illness.

Ted Walker, whose wife died from cancer, wrote in his book about the experience how she was very much part of his own self identity. On several occasions he experienced something relatively common in bereavement - that he thought he saw his wife:

“a phenomenon which took place on several occasions during bereavement: when you had the momentary illusion that you might come across the lost loved one again in just such a fashion; she was merely temporarily misplaced, waiting to be found again, with her own identity intact, as well as that large part of yours which she represented.” (Walker 1992, p.64)

Corbin and Strauss (1988) describe well spouses as ‘in a sense a mirror image of their ill mates’ (Corbin and Strauss 1988). The illness and the way the patient reacts to the
illness sets the conditions which are reflected in the way the well partner experiences it. Corbin and Strauss (1988) believe that the impact of illness on the family cannot be understood without looking at it in relation to the patient. These authors initially focused only on the partners of chronically ill people before including the patients to complete the picture. Their review of the literature reports that although partners also experienced the grave consequences of chronic illness, there was little assistance for them to deal with their own needs.

**The therapeutic benefits of social support**

Naturally, the majority of literature about cancer focuses on the patient. Where families are included this it is not necessarily to consider the families' own well-being, but rather it is frequently on the assumption that as the patient lives longer and increasingly spends the majority of their illness at home then those who support the patient at home need to be able to care for them adequately (Neuling and Winefield 1988; Cull 1991; Ramirez et al. 1998).

Spiegel and colleagues (1983) looked at family environment as a predictor of adjustment to metastatic breast cancer. Women were asked to complete psychological questionnaires which looked at among other things, family environment, mood and belief systems. The findings of the study reflect the authors clinical observations that optimal adjustment by the patient to metastatic breast cancer is facilitated by families which encouraged open discussion of feelings and problems whilst minimising conflict (Spiegel et al. 1983). Listening and talking with the patient about the disease (Smith et al. 1985) and warm supportive close relationships (Lichtman et al. 1988) have also been shown to be beneficial to women with breast cancer.

These studies are indicative of a general view that it is the family's responsibility to care for the patient's emotional well-being as well as their physical needs. Wortman and Dunkle-Schetter (1979) focused on the impact of close relationships on the patient's emotional adjustment to cancer. They believed that the cancer patient had a particular need for social support, given the 'web of fears' (p.125) engendered by the disease and
its treatment. They found that the social support available to the patient was likely to be
determined by two things: the nature of the pre-existing relationships between the
patient and those who are close to them and also the way that the family and friends
believe that they should behave when someone has been diagnosed with cancer
(Wortman and Dunkel-Schetter 1979). Wortman and Dunkle-Shetter suggest those
close to the patient are likely to experience negative feelings about the cancer and the
patient's situation whilst believing that it is important to be cheerful, encouraging and
optimistic when interacting with the patient. For the patient, this may mean that they
experience awkward, superficial interactions from close family with a potential for
discrepancy between their verbal and non-verbal behaviour. This is obviously not
supportive. It does however highlight the conflict that many relatives themselves may
experience with anxieties that they may do or say the wrong thing and a belief that they
need to repress their own difficult feelings.

Peters-Golden (1982) interviewed a healthy population and also found the fear of saying
the wrong thing to a person with cancer, thus creating the potential for awkward
communication which may in fact harm the patient rather than providing them with
support. In addition a comparison population who were interviewed following surgery
with breast cancer found that the support that was extended to them was often
inappropriate because of a mistaken assumption that the loss of a breast was more
devastating for a woman than the diagnosis of cancer (Peters-Golden 1982).

In a study of couples' adjustment to breast cancer and benign breast disease (Northouse
et al. 1998) significant decreases were found in social support over time. The greatest
drop in social support was for the husbands of cancer patients 60 days post-diagnosis
when many of the demands of the diagnosis of breast cancer and its ongoing treatment
were still high. The authors of this study explain this by the fact that the husbands may
be perceived as care providers rather than as people who themselves are in need of care
and support.
A further study which affirms the assumption that a supportive marital relationship is important for the patient’s psycho-social adjustment indicated that husbands could make an early prediction of patients who may be at high risk of maladjustment to breast cancer. The husbands were regarded as a resource for planning the rehabilitation of their wives but not necessarily regarded as in need of support for themselves (Omne-Ponten et al. 1995).

Caring

'Care' or 'caring' are difficult terms to use because they are so widely applied to such a variety of situations, and mean different things to different people. For the purpose of this study the term carer was deliberately avoided to describe the relatives because it may imply that these close relatives are the people that will be giving the care, and thus might not expect to receive any care for themselves. However, there is an extensive literature on caring, some of which is obviously relevant here.

The experience of 'carers' at home has to some extent become politicised with public debate about the carers own need for support (Ungerson 1992; Henwood 1998). The majority of people in Britain who define themselves as carers are women (Twigg 1992; Henwood 1998). Feminists have argued that this hidden domestic labour needs recognition for its contribution to society (James 1998). Nevertheless carers are a heterogeneous group and many who do provide care may not recognise themselves as belonging to a group of 'carers' (James 1998) as, for example, the husband or wife of someone who has cancer. A person with cancer may also find it difficult to accept that their close family and friends have become their 'carers'. Schumacher (1996) who interviewed patients and family during chemotherapy found self-care and caregiving were interconnected patterns of behaviour, with the requirements of the caregiving role waxing and waning during chemotherapy. The people with cancer who took part in her study 'often vigorously resisted receiving help from others and strongly desired to maintain their self-care' (Schumacher 1996, p.263).
Care has been discussed extensively in the sociology and nursing literature. The title of Corbin and Strauss' (1988) study of living with chronic illness 'Unending work and care' gives an indication of their analysis of the ways of managing long term health problems in the home. The authors interviewed in depth sixty couples who were experiencing a range of chronic illnesses and looked at the 'continuous accommodation' (p.5) attempted by patient's spouses in struggling to maintain some balance and give meaning to their respective lives. The book uses the notion of work to organise the many different components of managing the illness. For example as well as practical work there are also biographical types of work involving defining and maintaining identity - making the illness part of the life of the patient and their relative. If the well partner becomes overloaded and a high proportion of their resources are being used to sustain life on a basic level, then there may be little reserve to manage the biographical work which Corbin and Strauss see as important for maintaining oneself and one's partner and the relationship against the accumulated stresses of chronic illness.

Corbin and Strauss (1988) list the conditions which may lead to strain in the partner of the patient. These include the severity of the illness and degree of the patient's physical failure, and how well the patient themselves can live with the illness and also the work style that the couple develop together. Additionally they comment that, among other things the well partner may want to spare their spouses already drained emotional resources and so hide their own feelings.

Corbin and Strauss's analysis of living with chronic illness in many respects presents a very negative experience. Commenting on the wide range of problems faced by the partners of people who are ill, they write:

"One can see why they feel frustrated, angry, baffled, isolated, guilty, biographically blocked, worn out, exhausted, financially strained. It is not hard to imagine how they begin to feel trapped, desperate, and pushed to their limits of tolerance, so that the stress begins to manifest itself in overeating, drinking, illness, allergies and skin rashes such as hives, verbal and other emotional abuse of the ill person." (Corbin and Strauss 1988, p.298)
In Corbin and Strauss' study the experiences described are of an illness which goes on and on with little chance of resolution. A few of the participants in the study did have cancer. Cancer may become a chronic illness with relapse and remission, continuing levels of uncertainty and a level of disability, this is particularly likely in diseases such as breast cancer. However, the description of 'unending work and care' may be less appropriate for the majority of cancers. Some resolution is more probable - either by death or even by cure or long term remission. The physical burden is likely to be less arduous and although there are increased emotional tensions, loss of the patients’ mental function is unusual except when the brain is affected by disease. Finally, in considering the relevance of Corbin and Strauss's study to this thesis, although their study was initially intended to focus on the experience of the partners, ultimately it too came to be predominantly about the well-being of the patient.

When randomly surveyed in a large study of quality of care for people who died from cancer in the UK in 1990 bereaved family and friends did give some indication of their own experience of caring (Addington-Hall and McCarthy 1995). This research found that patients spent most of their last year at home, (with 55% spending less than one month in hospital). One third (36%) of the relatives, friends or neighbours who helped to care for the patient found that this had severely restricted their activities. Interestingly, half the carers (53%) said that they had found looking after the patient rewarding - although it is not clear in what way, whilst only 7% found it a burden. Nevertheless, one third (37%) of the carers said that they themselves had health problems which had made caring for the patient difficult. Analysis of this and earlier data found that care was experienced as more burdensome by the relatives who were not married to the patient (Seale and Addington-Hall 1995).

Several authors have examined the burden of care for the families of cancer patients. Two studies looking at the demands of care for the families of cancer patients receiving outpatient treatment found that giving emotional support was among the most time consuming tasks (Oberst et al. 1989; Carey et al. 1991). Giving emotional support
received the highest burden score for the family members of those receiving chemotherapy (Carey et al, 1991). These studies both developed scales which looked at the variables associated with caregiver mood. Poor health, less education and lower socio-economic status led the caregivers of patients receiving radiotherapy to appraise their own situation as most harmful or threatening, with older carers seeming to be more accepting of the illness (Oberst et al, 1989). Perhaps surprisingly, concern about the patient's mental state rather than practical and physical tasks was also found to be more of a preoccupation of the carers of people with stroke, who were also distressed about restrictions on their own social lives (Anderson 1988). Indeed, McCorkle and colleagues (1993) in a longitudinal study which measured the relationship between patient psycho-social responses and care-giver burden, found that the care-givers of patients with worse mental health and greater levels of depression overall experienced more responsibility for physical care of the patient and a greater impact on their own daily life, finances and health (McCorkle et al. 1993). In this study the people with cancer who took part had complex care needs and initially when the patients were discharged it was their physical needs with which the care-giver burden correlated most closely. However, on further investigation at three and six months the patient’s psychological well-being (even when it was improving) had the most impact on the level of burden that the carers experienced. (McCorkle et al, 1993). Depression in the person with cancer was related to depression in the caregiver in another study which also illustrated feelings of helplessness in the carer when the patient’s symptoms were not controlled (Given et al. 1988).

In the studies described above little information has been reported about how the family themselves might feel about the situation and how this impacts on their own life. James (1989) defines the work involved with dealing with other people’s feelings as ‘emotional labour’:

“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, p.19)
James (1989) argues that there are certain learned skills that may be applied to emotional labour which, if used, may give a better outcome both for the person caring and for the person cared for. James’ own research led her to an ethnographic study of professional care in a hospice and she compares the elements of this closely with women’s domestic care in the home. James, defines care as ‘Care = organisation + physical labour + emotional labour’. She asserts that where modern death is more likely to take place in an institution, health professionals are now doing the ‘work’ that was previously undertaken by the family (James 1989).

Nevertheless James finds that the ideology of family care which has been taken up by the hospices is vulnerable to institutional constraints. Family care is an integral part of the intimacy of the family, so that ‘caring for’ is assumed from a relationship of ‘caring about’. In the workplace priorities act to respond to the dominant group or the community as a whole rather than to the needs of the individual, thus ‘being’ with and spending time with someone who has no immediate physical needs takes a lower priority. Therefore professional care may never be able to replace family care in the same way. The professionals may emulate elements of family care but in most instances only actively intervene or take over when family caring is absent or has been disrupted in some way. James (1989) believes that the product of caring when done well is invisible. It is often only recognised when things go wrong or become disordered.

*Physical and psychological symptoms experienced by those close to a person with cancer*

The fear of loss through bereavement may be an additional stress on top of others which may be associated with caring. The fact of caring about someone, if not actually doing anything for them, may create distress which has a physical manifestation.

In a study of 207 bereaved carers who undertook a semi-structured interview about what had happened in the four weeks before death it was found that most of these carers developed symptoms during the terminal phase of the illness (Jones et al. 1993). Ninety
Carers experienced sleep problems, 82 had lost weight and 60 said that they had been nervous and anxious. These symptoms were rarely mentioned to a doctor because the carers did not believe that they were severe enough. Only 48 of 207 carers had no symptoms. Others believed that the doctors and nurses would ask them about their own health if it were important.

Oberst and James (1985) found that the somatic complaints of a patient's spouse began to escalate between 30 and 60 days after the patients came home from surgery. In addition to generalised fatigue these complaints included; indigestion and food intolerance, vague diffuse aches and pains, exacerbation of pre-existing medical conditions and a variety of minor ailments. Nevertheless, the authors report that the patients were virtually unaware of their spouses' distress (Oberst and James 1985).

The extreme tiredness felt by the carers of people with cancer may arise for a variety of reasons and be cumulative as the cancer progresses. Sleep may become very interrupted and the carer vulnerable to a variety of illnesses (Young and Cullen 1996). In their study about the experience of death in east London Young and Cullen (1996) acknowledge the conflict in the minds of some of the carer participants, between the wish that their loved one would never die and the guilt of thinking of the relief that death might bring. In this small sample (fourteen), it seemed that those patients who were well supported by family lived longer. However, Young and Cullen also comment that a good death (and here they include a prolonged death) for the patient can make for a bad bereavement. It is postulated that this is because the carers may have become so worn down and tired that recovery is even more difficult. Furthermore, the carer's lives may have become so intertwined with that of the sick person that they may be slow to be able to move towards any sort of independent living (Young and Cullen, 1996).

There are undoubtedly both negative and positive elements to caring for a close relative with cancer (Nijboer et al. 1998). Nijboer and colleagues believe that there has been very little research addressing the positive aspects of caring for cancer patients. In a review of the literature on the possible impact on health of caring for cancer patients,
they theorise that the individual carer’s personality and unique perception of the illness are related to the effects of the illness on their health. Thus the extent to which the situation is experienced as stressful depends on the demands and resources as perceived by each carer (Nijboer et al, 1998). Partners are identified as the most vulnerable caregivers in contrast to other relatives. Specific types of care such as support and personal care may be more burdensome than additional household duties and thus the authors suggest these activities may have a more negative effect on health. However, little is known about the changes in carers health in relation to the course of the illness and indeed carers health may fluctuate in response to the patient’s physical well-being. (Nijboer et al, 1998).

The focus of Benner and Wrubel’s (1989) book, ‘The Primacy of Caring’, is essentially about nursing. Benner and Wrubel believe that ‘involved caring’ is important for expert nursing practice. ‘Burnout’ as late effect of caring involving exhaustion with a loss of energy, loss of connection and extreme fatigue, is discussed with reference to both professional and family caregivers. Burnout may lead to avoidance of the patient and is a sign of the need for respite or distraction and reconnection to sustaining relationships. This may not require a dramatic change, these authors cite an example of a mother who found distraction and comfort through the mundane but normal activity of knitting at her dying daughter’s bedside (Benner and Wrubel 1989).

The family and the professional carers

Earlier in this chapter some of the issues pertinent to the professionals caring for a person with cancer and their family have been explored. Here studies which look at the relationship with the professional carers from the relatives’ point of view are addressed. Perhaps not surprisingly one of the most frequently stated findings is that the relatives own well-being is improved when they perceive that the patient is being well cared for (Hull 1991; Field et al. 1992).

Many of these studies concern the relatives of terminally ill patients or bereaved relatives. In the UK several studies involve asking the bereaved relatives to comment on
their experience of seriously ill patients in order to examine not their own but the patient's experiences of professional care (Addington-Hall et al. 1991; Sykes et al. 1992; Fakhoury et al. 1997; Seale and Kelly 1997a). This approach is taken because of the difficulties associated with approaching the dying patients themselves (Hopwood et al. 1994; Plant et al. in press). There is debate over the relative merits of using bereaved family members as a valid proxy for a patient's assessment of dying, with the concern that family members' recollections of the experience may change during their bereavement (Higginson et al. 1994). Field and colleagues (1995) who interviewed patients and their lay carers prior to death suggest that the carers' accounts of the patient's experience are indeed a valid source of information. They found no statistically significant differences between patients and carers with regard to questions concerning activities of daily living, physical symptoms or the evaluations of professional care (Field et al. 1995). Field et al (1995) do however acknowledge the body of evidence which indicates that the lay carers report higher levels of psychological symptoms in the patient and higher levels of distress due to physical symptoms than the sick person themself. For example, Higginson et al (1990) found that the family members ratings of patients symptoms were higher than those of the patient themselves particularly for pain and the effect of anxiety on the patient. Both patients and family identified the effect of anxiety on the family as one of the two most severe problems (Higginson et al. 1990). Field and colleagues comment that the question of whose account may be true is potentially a fruitless one since both accounts may have their own bias but nevertheless may be a true reflection of differing aspects of the experience of dying (Field et al, 1995, p.53).

These papers are not really focused on the carer's experiences per se, although obviously there are important questions to be answered and the studies do throw some light on the relatives' states of mind.

There are several studies which set out to look at the relatives' perspective on their own care from the professional carers (Field et al. 1992; Seale and Kelly 1997b). Seale and Kelly compare care for the bereaved spouses provided by hospice and hospital and
found no significant differences (Seale and Kelly, 1997b). Again the focus is with the patient - how many visitors should be allowed, and the benefits for the relatives of being involved with the patient's physical care. Higginson and associates (1990) using a questionnaire to rate problems and services for terminally ill cancer patients and their families concluded that the needs of the family may exceed those of the patient. Higginson et al, supporting the suggestion of Gilley (Gilley 1988), comment that 'the carer or family member needs to be 'emotionally held' by the professional carer during the nurturing of a dying patient (Higginson et al. 1990, p.280).

In a study to examine the caring behaviour of hospice home care nurses, ten families took part in repeated interviews about their experiences (Hull 1991). Four key areas of caring by hospice home care nurses were identified: 24 hour accessibility through the telephone, effective communication skills, a non-judgmental attitude and clinical competence (see Accessible and Approachable Professional Care, chapter seven).

Many of the studies which look at care throughout the illness trajectory are from North America. Lewandowski and Jones (1988) attempted to look at nursing interventions that might be helpful to the family throughout the course of the illness (Lewandanski and Jones 1988). This study identified people through a random sample of households taken from the telephone directory. Respondents were asked to answer questions based on vignettes of three stages of cancer: an initial, an adaptation and a terminal phase. The participants expressed a consistent desire for nursing interventions to be directed towards the patient rather than themselves. As in other studies for example, (Wright and Dyke 1984) nursing interventions which were aimed at giving information were rated as highly desirable throughout the course of the illness (Lewandowski and Jones, 1988). Tringali (1986), found that to have questions answered honestly was the highest ranked cognitive need by the 25 family members who rated the importance of 53 need statements and this applied in all phases of the illness (Tringali 1986). Hinds (1985), used a semi-structured interview with relatives at home to identify the needs of families who were providing patient care. Needs were frequently for information on acquiring the skills required to carry out caring tasks (Hinds 1985). Families seldom sought help from
professionals for their own social and emotional needs, although the need most frequently expressed by the families in the psychosocial domain was for a place where they could turn to discuss their fears (Hinds, 1985).

The families of patients with cancer sometimes ask health professionals for information about the patient’s state of health and prognosis without the patient’s knowledge. The relatives may also wish to modify the information which is given by the professionals to the patient (Benson and Britten 1996). In order to determine how patients themselves might want their doctors to behave when the family request information about their disease and its treatment, 30 people with cancer took part in taped interviews to elicit their views on these difficult issues. This study found that the patients were unanimous in the view that their own opinion concerning confidentiality and giving truthful information should take precedence over their family. All but two patients rejected their family’s right to influence the information that they received. The authors comment that a prescriptive solution as to how these choices should be made is not the answer and that “patient’s views about appropriate disclosure and provision of information may depend on details of circumstance” (Benson and Britten, 1996, p.731). This illustrates the substantial change in the last 30 years from the situation where the relative knew that a person may be dying but the patient did not (the closed awareness of Glaser and Strauss (1965)), to a situation where patients expect to take some control and know all details of their treatment, and even their death (Field 1996).

In a study which interviewed carers about what had happened in the four weeks before a death at home from cancer, the authors comment that many of the doctors and nurses involved seemed unaware of the problems that the relatives themselves may be experiencing (Jones et al. 1993). Field and colleagues interviewed carers a week after the patient had been admitted to a hospice, and then repeated the interviews with over half of these three months after death. These authors were concerned that the professional health workers were unable to ‘adequately recognise the plurality and diversity of lay carers involved with patients.’ (Field et al. 1992).
Corbin and Strauss (1988) cite an inadequacy in service provision to address the relatives’ needs and also a lack of uptake of the provision that is available. They postulate that the reasons for the latter are that carers are not aware of these services or that they believe that they need to pay for them. Family responsibility may prevent partners from calling on others as well as a lack of self awareness about how stressed they have become. These are issues particularly relevant to this current research and will be addressed in chapter seven.

A qualitative study involving semi-structured interviews with 32 carers of people with cancer revealed that these carers willingly (on the whole) undertook a range of tasks to support the patient (Walker et al 1993). The participants stressed the importance of regarding the carer as an individual through good communication, particularly by listening to what the close relative had to say. Some expressed the need to protect the person with cancer from their own high levels of anxiety, with their experience often being coloured by a particularly significant experience with the professionals where the carers felt that something had gone wrong.

North (1997), writing of her own experience as the wife of someone who underwent treatment for a brain tumour, offers some advice to health professionals;

“There needs to be an awareness that the carer is also having to find the strength to cope, and is probably very frightened even if they do not show it when they are seen with the patient. It is important to ask them how they are.” (North 1997, p.79)

Qualitative studies about the family’s experience of cancer

There are a number of qualitative studies about the experiences of the families of people with cancer. These identify some of the ways that the families live through these potentially difficult experiences. These studies and others cited later in the text provide a useful point of comparison with the findings from this interview study. The most relevant studies are mainly from the nursing literature.
Thorne (1985), undertook a series of group interviews with eight families which included the person diagnosed with cancer. Here all the families, despite their individual differences, described how they had found strategies to maintain ‘normal’ lives - whatever this meant for them. Thorne found that despite the sometimes apparent contradictions in their collective account, underneath there was a shared family philosophy or mutual value system which allowed them to find meaning in the experience and incorporate the disruption into their lives. Nevertheless the styles that families found to be helpful did not necessarily conform to the professional view of successful adaptation, and the families did not necessarily need or want any outside help for managing this (Thorne 1985).

Rose and colleagues interviewed families caring for a terminally ill patient (Rose et al. 1997). These families were interviewed on several occasions and the authors, also described some of the coping strategies that the carers achieved. They focused on three in particular, starting with denial - well described as a way of dealing with difficult situations (Parkes 1975; Kubler-Ross 1996). ‘Denial’ does allow families to keep going and affords some comfort, nevertheless, Rose et al described this as ‘ultimately destructive’, because of the isolation created by not acknowledging the truth of the situation. Here, as in Thorne’s (1985) work, Rose et al also identify normalising as a way of reducing the problem and making it more manageable. A further research study which interviewed women who had recently had surgery for breast cancer and their families also found that participants identified ‘normalisation’ as a major family coping strategy (Hilton 1996). Hilton defined normalisation as, ‘strategies that minimise the effects of the impairment while still acknowledging the seriousness of the situation and its inherent dangers.’ This is obviously a different situation when the person with cancer is relatively newly diagnosed and has undergone hopefully curative treatment to that when the patient is terminally ill.

Rose and colleagues identified a third way of coping with the illness which they described as ‘togetherness’. A unique example in their study was of a couple openly facing the wife’s death together. Here rather than the husband being busy in his caring
role this couple found time to be together; the husband is quoted as saying: ‘It is important to be still sometimes’ (Rose et al, 1997 p.131). This couple did not want outsiders to come in and manage this precious time, the husband without question took on caring for his wife as a continuation of their close relationship. Rose and colleagues comment:

"it was not so much a moral duty to care, but the naturally and unquestionably right course of action." (Rose et al, 1997 p.131)

A further qualitative study involved interviewing both patients and partners two to nine months after a diagnosis of lung cancer (Cooper 1984). About half of the participants, both patients and spouses appeared to be using a degree of denial as a coping mechanism. This study of 15 couples found that most of the spouses were not sharing their fears and concerns with the patients. Cooper expresses a possible explanation for this:

"while the patients may have felt free to talk whenever they liked, the spouses may have been conscious of holding back in order to protect the patient and, consequently they believed that they were talking less frequently." (Cooper, 1984, p. 303)

Cooper (1984) also found that twice as many spouses as patients showed signs of stress, for example sleeplessness, loss of appetite or inability to concentrate but the needs of the patient took precedence over their own.

These papers give a picture of close family members who are very distressed but who do not break down and who manage to find ways of living with the illness to minimise the disturbance. This may require a great emotional effort on the part of the relatives and possibly the repression of their own feelings. The ways these families cope however does not necessarily conform with the ways that the professionals might think was most appropriate for them. These papers beg the professionals to question their assumptions about what the relatives might need from them and suggest sensitivity to the individual’s ways of living with the illness.
Ferrell and colleagues (1991), when examining how the family’s perceptions of pain influenced cancer pain management at home found that one of the ways the caregivers coped with the illness was by hiding the emotions associated with the pain. They also hid the guilt associated with the caregivers' wish for the patients suffering to end with death (Ferrell et al. 1991). Northouse and Northouse’s (1987) review describes how family members may conceal their feelings from each other with the result that they may often bear their emotional pain alone (Northouse and Northouse 1987). Vess and colleagues (1988) interviewed patients and their partners admitted to an oncology service and found both to be stressed by concealing concerns about the prognosis from each other (Vess et al. 1988). Here it is the patients in particular that are described as protecting their family from discussing fears and concerns that may upset the other and thus unable to talk with their partner as much as they might have liked to (Vess et al. 1988).

A further sociological study (Sabo et al. 1986) analysed men’s reactions to a partner’s mastectomy. Sabo and colleagues found intense emotional reactions at diagnosis with spouses’ major fear that the wife might die. Fear of the patient’s death may actually be more intense for the relative than for the person with cancer. Gotay (1984) audio taped interviews with women with early and advanced cancer and their male partners using both measurement scales and open-ended questions (Gotay 1984). This study found that the men were much more likely to be disturbed by the thought of the patient dying while for the women their own death did not appear to be a pre-eminent worry (Gotay, 1984). Fear of the future was most acute at diagnosis for the next of kin of hospitalised adult cancer patients who took part in a semi-structured interview study (Wright and Dyke 1984).

Davies (1997) tape recorded interviews separately with people with malignant glioma and one close relative. The relatives were found to be much more aware of the prognosis than the patients and were more active in seeking out information than the patients. Davies comments that this may be because the relative has to think of death
and beyond because they are going to survive (Davies and Hopkins 1997). Hinton (1998) who used semi-structured interviews in a prospective study of patients referred to hospice home care and their close relatives noted that patients and their relatives may react differently. Hinton comments that patients may want to ‘escape into the comfort of mental avoidance’, whilst their relatives ‘face possible loneliness, a prolonged sense of loss, and the prospect of having to cope somehow’ (Hinton 1998, p.23).

Hinds (1992) recorded semi-structured interviews at home with the family caregivers of people currently receiving treatment (Hinds 1992). Hinds explored the phenomenon of the family caregivers suffering, and presents her findings in the form of family profiles which display a range of emotions including uncertainty, helplessness and even abandonment. Many of the caregivers talked about not being able to escape from the disease, as one participant commented, ‘its on my mind all the time’ (Hinds 1992, p.922)

Like other research, the majority of qualitative studies tend to focus on the partner of the person with cancer. There is little reference to siblings or adult children. Hind (1992) quotes the 46 year old daughter of a woman with breast cancer:

“I am angry, mad, frustrated at the whole damn thing. You are unable to do anything about it except just be there. There is nothing you can do; its in the hands of God...........

You do get to the stage where you feel you have to run... just have to get away from it. Fear of what is going to happen to her and me. I have cystitis, I imagine doctor is not telling me the truth. Your mind gets out of whack... you think its cancer.” (Hinds 1992, p.921)

ILLNESS STORIES

This thesis is made up of peoples’ stories. I had not fully considered the implications of this when I embarked on the study. I wanted the participants in this research to be able to tell me what was on their mind without interference from any preconceived idea or hypothesis of mine. However, I did not appreciate the impact that recounting their experiences might have on the people taking part in the research, or the impact on
myself as the listener, or indeed how difficult trying to order the stories into an analysis might be.

The relating of events, even quite mundane ones, will often bring a degree of order and resolution. Indeed, there may be an urgency to relay more difficult experiences to someone who will acknowledge and empathise with what is being said. Not talking about things - keeping them bottled up - is often regarded as harmful.

In experiencing an episode of ill health this may be particularly pertinent. Good (1994) hypothesises that the imaginative linking of experiences and events into a meaningful story is a crucial personal and social effort to reconstruct life which is threatened by the potential destruction of a serious illness (Good 1994, p.118).

Stacey (1997) describes the feeling of isolation imposed by a trauma such as cancer, creating a need for others to ‘bear witness to the impact of the shock’ (p.16). Stacey comments that a forum such as a support group can provide ‘The feeling that ‘someone has heard my story’(p.16) and confirmation that it is legitimate to want to tell the story with the resulting calming of ‘the psyche.’ (Stacey 1997).

In the last few years the need for acknowledgement, to speak about and make sense of traumatic experiences - particularly illness has become a fecund source for publication. For example Oscar Moore’s ‘PWA’ in The Guardian, Ruth Picardie’s moving column about her experience of cancer in The Observer, John Diamond’s book, and column in the Times, Michele Petrone’s haunting picture and words about his diagnosis of and treatment for Hodgkin’s disease. (Moore 1996; Diamond 1998; Petrone 1998; Picardie 1998). Newspaper and journal publications have a wide readership and may make some impression on their readers. Public deliberations over difficult life experiences may be reflected in the feelings and reactions that people feel it is acceptable to explore in private. Blake Morrison (1993) in his account of his relationship with his father, written after his father’s death from bowel cancer, explains his need to share his experiences:
"I've become a death bore. I embarrass people at dinner parties with my morbidity.

Now I want to hear their death stories - the heart attacks, the car crashes, the cancers, the morgues." (Morrison 1993, p.205 - 206)

There are many published autobiographical accounts by people who have been ill. These present an individual, limited perspective and are written by a particular group of people who have both the need and the skill to be able to tell their story publicly. Conrad (1987) comments that these are generally limited by their lack of analysis or comparison with others, but can be useful as data (Conrad 1987). Individuals' accounts may provide a deep insight into that person's albeit idiosyncratic experience. Ben Roughton, a teenager with cancer, explained his reasons for writing a book:

"I am terminally ill with Cancer. That seems to me a fairly good reason to do something that will outlast me. My aim is that a few people will read this and what I say will connect with their experience. I hope at the very least they go away and think a bit more about life and what a strange thing it is."

And in the epilogue:

"My experiences have forced me to look at my life again, and to try to understand it." (Roughton 1997, p.5 and p.99)

Michael Korda's (1997) vivid account of treatment for prostate cancer also has a very clear messages for other men - to be vigilant about their prostate and that if they do have problems then they need to talk about it (Korda 1997). Helping others to learn through one's own experiences can give an important feeling of worth when it seems that other avenues of opportunity are closing. Stacey (1997) believes that publication can be kind of public recognition which bestows a form of empowerment on the author. Writing about one's illness is also a way of putting some boundaries on it, Mathieson and Stam (1995) write:

"In negotiating their way through regimens of treatment, changing bodies and disrupted lives, the telling of one's own story takes on a renewed urgency. In the end, they are more than just 'stories' but a vehicle for
making sense of, not an illness, but a life.” (Mathieson and Stam 1995, p.284).

Isabel Allende writes about her daughter’s illness because her unconscious daughter can no longer tell her own story. Allende is afraid that when her daughter wakes she will have somehow lost her identity. In writing Allende also finds some form of comfort for herself:

“I plunge into these pages in an irrational attempt to overcome my terror. I think that perhaps if I give form to this devastation I shall be able to help you, and myself, and that the meticulous exercise of writing can be our salvation.” (Allende 1994, p.9)

Although there have been several accounts by patients of living with a diagnosis of cancer, it is notable that less has been written about what this feels like for the family who are living with the illness. Ruth Picardie writes about her breast cancer distancing it and controlling it through black humour:

“Your chic crop turns into a toilet brush. You’re so grumpy and depressed you start believing your children would be better off without you, sooner rather than later. You even go off ER. Still, it ain’t over till the fat lady’s thin. Or until her liver packs in. Or something. Watch this wig.” (Picardie, 1998, p.39)

It is difficult to imagine those close to her having the opportunity to cope with her cancer in quite such a way. Most commonly when they write, the relatives stories have been written after the patient’s death. Picardie’s partner Matt Seaton did write very movingly in a posthumous collection of his wife’s writing:

“What claim have I to write here ...

of course, as the piece took shape, I realised I had my own reasons for writing. I wrote partly as therapy ....

What I wanted to achieve was to describe, in as clear-eyed a way as I knew how, the pain of losing someone dear in all its messy ambivalence....
there might be something truthful that could possibly be of use to somebody somewhere - a glimmer of recognition here, the pleasure of finding something previously felt but not previously named there". (Seaton 1998, p.97-98)

So, whilst with a diagnosis of cancer the relative's world may be devastated along with the patient's, the relatives may have less 'opportunity' to reflect on the experience except in retrospect. Those close to the person with cancer may only be able to begin to address what the illness has meant to them after the patient has died (For example, (Lewis 1961; Cooper 1989; Walker 1992). For these relatives the story does have an ending of sorts. The retelling of the story is told from the perspective of the death.

Two wives of men with brain tumours recount their experiences in a book published by the Royal College of Physicians aimed at improving patient care (Davies and Hopkins 1997). One woman is bereaved, the other writes from the perspective of 5 year survival. Judith North (1997) whose husband was diagnosed with cancer when he was 28 years old and survived against the odds comments:

"the experience of a partner or carer is a hard one to describe." (p.75)

She nevertheless makes a fine attempt at it. North discusses her fear and loneliness after her husband was diagnosed and then continues:

"A partner or carer may experience similar emotional swings to the patient, as well as some unexpected feelings like guilt, pity and inadequacy. But the partner or carer is often expected to carry their load, to suffer in silence and to be seen as coping. Family and friends often depend on the partner or carer to console and comfort them which seems an unfair burden at times. Without down-playing the difficulty of the patient's position, being a carer, either as partner or a relative, is probably the most challenging role a person will undertake in their life," (North 1997, p.77-79)

North deliberately includes the experience of her own emotional struggle. Chapple, whose husband died from a malignant cerebral glioma, writes with the patients' well-being at the forefront of her argument. Her husband lived for 18 months with his disease
and she describes her relationship with her husband 'as one' (p.30). She was told the news when her husband was still recovering from an anaesthetic and, "the protective instinct arose very fast to look after all those within my orbit." And later she comments:

"the few days while he was in hospital gave the only short spaces in which I could both express my deepest response to the news and come to terms with our life ahead." (Chapple 1997, p.30 )

Both women are writing because they are motivated to improve the care of people with brain tumours and their relatives and comment that they themselves received little support. Reflections on events are given a different slant after the patient has died or been cured. Undoubtedly this may have helped them to begin to make some sense of the experience. It is noteworthy that Chappell expresses the view that she was helped by taking part in the research on which this book is centred and that the period of her husband’s illness would have been much bleaker without it.

All the published accounts must be a later reconstruction of events – even the journalists such as Picardie, Moore and Diamond are not giving us the experience raw, it has been processed for consumption by a mass audience which has a deep fascination and tentative anxious identification with the personal struggle with such a universally dreaded disease. Despite this, these stories can of course create a vivid and emotive picture. Matt Seaton describes how cancer changed their lives:

"The cancer had interpolated itself, sending out its rogue cells to multiply madly and lay waste like an army of termites. Cancer changed everything: it put us on different tracks, stretching our grasp of one another to the limit and eventually forcing us apart. In the end, I could not reach her, and it felt like a failure in me. And then she was gone." (Seaton 1998, p.103-104)

Patients with cancer may use the albeit unwanted potential strengths of their situation to make a point, they may feel they have a right to be heard and people will listen. This may not be so for those close to them who have no such ‘opportunities’. A close friend of mine, Anne Dennison, felt a need to write about her experiences of ovarian cancer as one way of working through her reactions to the diagnosis, and to show others that it is
possible to enjoy life whilst living with the uncertainties of a terminal illness. Here Anne writes about the effect she believed living with her cancer had on her husband as she relapsed again, four years after her diagnosis:

“Paul was so reluctant to tell me but I knew anyway. Fatigue has worn him down. The constant uncertainty, the ever present threat that I am going to die, has turned him away from me a little. It is so hard to remain committed to someone, not knowing whether they will be there in a few months or a few years time. I can understand that. And the uncertainty goes on and on. The tenderness when I was first diagnosed couldn’t possibly be sustained without a break for nearly four years. I didn’t expect or want it to. It would have been easier if I had either died or been cured quickly but it just isn’t like that.

In a sense Paul is going through the same painful process of adjusting to this latest progression that I have had. The same resentment to the sharp cutting off of a relaxed attitude to life and an indefinite future. Anger at the possibilities we can’t choose any more.........................

It would be easier if I was less demanding, more oblivious, but I can’t be. I have to be myself. More so perhaps now that I am under threat. I don’t have the time, the patience to be untrue. That is part of the problem too. It hasn’t been all bad. Cancer has given me opportunities for self development and I have taken them with both hands. ....

But Paul has been holding back, simply because I have cancer. I was angry when he said that, how could he be so patronising. I felt a little guilty too. I hadn’t seen what was my advantage not to see.” (Dennison 1996, pp. 84 -85)

SUMMARY

There is a wide ranging literature from a number of disciplines which has relevance to the experience of those close to someone diagnosed with cancer. This chapter draws on this and provides background information about cancer highlighting the particular fears and stigma associated with this disease both for professional and lay people. However, whilst there is an increasing awareness of the social and emotional issues engendered by cancer there is no current consensus on how to identify or make provision for this. Much of the emphasis has been on ways of measuring this distress and less on determining applicable forms of support. Furthermore, although there is almost
universal acknowledgement that the distress for the family may be as great or greater than that of the person with cancer, there are few studies which address this. When studies do consider the family this is frequently in the terminal phase of the illness, and the person with cancer often remains the focus of attention.

Some theoretical perspectives on the family have been addressed, as has literature on social support and the difficulties of caring. This begins to illuminate the experience of the participants in this research. The few qualitative studies about the family of people with cancer, indicate the emotional effort required by the relatives. Finally current interest in the media for personal stories about cancer potentially provides a greater insight into the experience and begins to break taboos. Despite this there is still relatively little opportunity for the relative’s voice to emerge until the experience of living with cancer appears to be ‘over’.
Chapter 3
THE RESEARCH PROCESS
INTRODUCTION

This chapter presents the story of my methods and the methodological development of the thesis. It is, therefore, more a record of process rather than a clear cut summary of my methodological stance, although I will venture a brief summary of my overall approach at the end of the chapter.

I have chosen to put the emphasis on the journey rather than the destination for two reasons. First and foremost I want the account to be an honest one. I did not begin this research with a methodological stance and to the extent that I ended it with a stance it is one that emerged through a messy series of choices and compromises. The methodology is all the things I did over this period – it is the journey. To present it with a tidy label would seem to me to misrepresent it. Second, when it comes to attaching a label to my methodological approach I could not easily find a satisfactory one. I have tried to learn lessons from a range of approaches but I have never felt that I could wholly identify with any one approach. Therefore it seemed to be helpful to set out how the route I ended up taking drew from, or was in tension with, well known approaches in qualitative research. The resulting collage is, I hope, a useful corrective and complement to the tidy summary with which I conclude.

The aim of this research was to look at the experiences of people who were close to someone who had been diagnosed with cancer, to understand what the experience was like for these people at home and how this might change over time. This is a very broad and open ended aim which does not translate easily into specific research objectives. My primary concern has been to capture the first-hand experience of close relatives and to make some sense of this to a wider audience, rather than to assess their psychological well-being or to test pre-existing theory.

Research methods are not, and cannot be, adopted pure and unchanging from a text book. In this research I have been particularly conscious of a process of evolution, and of a range of elements that have induced or necessitated change. Institutional
constraints, practical experiences of relative ‘failure’ and ‘success’, theoretical reflection, as well as the deliberate self-conscious adaptation and modification intrinsic to the methods chosen have all had a part to play.

In writing about the process of the research, the methods and the analysis which influenced these methods will be linked closely together. The grounds for arriving at and monitoring the methods are important in illuminating the reality of the participant’s lives. Thus the discussion of the methods will also show how the process of the research itself revealed the experience of those close to someone diagnosed with cancer; their vulnerability, their support needs and the conflicts and complexities of their experience. The research participants have therefore been introduced relatively early in this chapter so that they may be included in the ensuing discussion of the influences on the process of this research.

A FALSE START

There were constraints in setting up this research. My post was funded as part of a larger project, the parameters of which had been established before I was appointed. I did not have a free choice about how and where the research would be conducted.

The project to which my funding was linked was looking at patients’ perception of need and relief in the first year after a diagnosis of cancer (Bliss and Johnson 1993). The patients in this project were interviewed twice using the critical incident technique derived from Flanagan (Flanagan 1954) and adapted by Bliss and Ogborn (Bliss and Ogborn 1987). The participants were asked to give accounts of events, either good or bad, that had been particularly significant to them since their diagnosis (Bliss and Johnson 1993). The critical incident technique has been increasingly used by nurses as a means of looking at nurses’ own perceptions of their work (Benner 1984; Johnson 1990; Wilde 1992). This method has also been used to elicit indicators of high and low quality nursing care from patients (Norman et al. 1992). Nevertheless, there was little experience of using this method to look at patient’s perceptions of their situation.
I wanted to focus my own research on the experiences of those people who were close to someone who had been diagnosed with cancer. It was thus practical, having gained access and interviewed people with cancer for the main project, to negotiate for their family and friends to take part in my study, rather than seeking relatives of people with cancer unconnected with the other study. Although my own work was going to be about the family, it also seemed important to interview both the patient and their relatives in order to gather a further dimension on the relatives’ experience (Conrad 1987).

Initially I planned to interview the relatives using the same method as the patient interview. To facilitate comparative analysis an interview script was to be adhered to and each participant was asked exactly the same questions. It was considered important that the interviewer remained neutral and detached giving nothing away that might bias the data. This included feigning a lack of knowledge about cancer and its treatments in order to obtain an ‘uncontaminated’ picture of the participant’s perception of the situation.

The early experience of interviewing the patients was invaluable in formulating the way in which I eventually pursued my own study. Over the first few interviews I began to despair that I would ever get the participants to fully co-operate with what I was asking them to do; they were consistently unable to keep their recollections specifically to good and bad incidents. The method of analysis which had been proposed (Systemic network analysis, (Bliss et al. 1983) did not allow the inclusion of these spontaneous unelicited stories which the participants were recounting, nonetheless, these often appeared to be the most illuminating part of the data.

This dilemma was exemplified when, having interviewed several people with cancer, I approached someone identified as close to the patient to take part in my own project. Using my carefully worded manuscript, I explained that I would like to interview her because I was doing some research about the experiences of the relatives of cancer patients and that I would like to know how things had been from her point of view.
In response, this woman became very tearful and quite distressed. She intimated that her role was to care for her husband and she could not allow herself to think about her own situation because she might then not be able to cope. She felt she must never let her husband see her distress. Indeed her husband had appeared to fail to grasp why I was interested in her as it was he who was the patient. The whole episode was ample confirmation of why I should undertake this research. However, I left the house feeling I had upset her equilibrium in some way. I had failed to obtain an interview and, given the research philosophy I was working under at the time, none of the interaction could be classed as data. I myself was close to tears on the way home.

There thus appeared to be three fundamental problems that I needed to address in planning this research.

i) To find a method of data collection which met with the aims of this study, but was also compatible with the ways in which people expressed themselves about their experiences; and which would also allow them to talk about the things that they felt were important and keep these experiences in context.

ii) To be able to include all the data in the analysis, including details surrounding the taped interview and my own reflections on the experience.

iii) To allow me to be flexible in my interactions with people who may be in very distressing situations.

I also changed my academic supervisor at this juncture.

THE RESEARCH APPROACH

After further review of the literature and helpful discussion with other researchers I changed my method of data collection and analysis (see Table 1). This section details
the research approach. In the second half of this chapter some of the influences upon this approach are considered in greater depth.

Twenty six people took part in the research with a total of 57 interviews. I interviewed both the person with cancer and those close to them whilst undertaking this research. As it is the relatives who are the focus of this study, they are referred to by the term ‘participant’. The interviews with the patient were used to provide context for the relatives’ experience and when included in the analysis they will be described by their study name, or occasionally as ‘patient participant’.

The research methods ultimately used in this study were the outcome of a number of evolving processes. The data collection in particular drew upon my experience as a cancer nurse which was ‘liberated’ by letting go of the initial research model. This evolution was also enabled by and drew upon a range of sociological work in qualitative research: grounded theory, ethnography and feminism all of which influenced and overlapped in the process of collecting these data.

The approach taken to structure the data collection and analysis was based on grounded theory (Glaser and Strauss 1967). Grounded theory provides a systematic framework for the simultaneous collection and analysis of data. Thus interpretation and analysis could begin from what was emerging from the data rather than from any preconceived idea, theory or hypothesis. This was crucial in a study where the aim was to look at everyday experience. As the data was collected the important issues emerging for the participants could dictate how the study would progress.

This method also allowed for the variance of data collected in the natural setting. It has a potential to include all of the interaction with the participant during the research, even allowing the inclusion of things intimated but left unsaid. Furthermore it facilitated the continuous comparison of concepts which were emerging from other interviews (Strauss and Corbin 1990). It was hoped that this study would be able to look at people’s experiences in depth and also how their perceptions changed with time. Recurrent data
collection gave me an opportunity to develop rapport with the participants and more importantly to go back to the individual, and test ideas, and explore what they had meant in their previous interviews (Laslett and Rapoport 1975). It had become clear very early in the process of interviewing that the research was having quite a profound effect on some of the participants. It was also apparent that I had as many different and unique relationships as there were participants in the research. Rather than denying this it seemed more profitable to set up the research to include these interactions in the process of analysis. These data about my relationships with the participants and their reflections on the research process were some of the most revealing about the experiences of someone close to a person diagnosed with cancer.
DATA COLLECTION

Access

• patients with common cancers were interviewed three months after diagnosis
• consent from patient was obtained to approach relatives
• all interviews took place in participants’ homes

Pre interview commentary recorded by researcher

• details of negotiating access

Interviews

• at three, seven, thirteen months after diagnosis
• bereavement interview, where possible, if patient died during study period
• no time limit on taped interviews, most last approx. 45-90 mins

Post interview questionnaire completed with participant recorded

• demographic details
• effect of interview on participant
• debriefing

Post interview commentary completed by researcher recorded

• details of interruptions, hospitality,
• questions asked,
• time of day,
• length of visit etc.

Taped field notes recorded impressions of the interview

Field notes from phone calls, letters etc.

Memos

Table 1. Data Collection
**Role of Researcher**

The data here was collected as far as feasible using ethnographic procedures (Hammersley and Atkinson 1995). Interviewing is just one possible element of an ethnography, and is in itself an artificial intrusion into the lives of those who are taking part in research. However, the reflexivity of the ethnographic process was used throughout the whole of the interaction with the participants in order to keep the recorded interview in context. I became part of the social world I was studying albeit for a short period. I have thus influenced the data I collected. Working either as an automaton with a script, or a neutral vessel who embraces the experience without causing a ripple was an impossibility (Hammersley and Atkinson, 1995). I myself was the research instrument.

The basis of rigour in ethnography is achieved by a self-conscious reflection on and between the social relationships with participants and the technical mechanisms of data collection (Ball 1990). For example, in this study, how far the participants perceived me as a nurse and a potential source of information in my social interaction with them may reflect on the material they provided in the technical collection of the data, the taped interview.

It was therefore important to be constantly aware of my own motives, training and social background, and how this influenced the ways in which I interacted with the participants and interpreted their experience. Klienman (1988) comments;

> "Clinicians (and researchers, too) need to unpack their own interpretative schemes, which are portmanteaus filled with personal and cultural biases. They must also rethink the versions of the clinical world they create. They must be certain where therapeutic interests are being altered by concerns of theory validation, research publication, or just plain making a living and advancing a professional career." (Klienman 1988, p.53).

Good (1994) describes how when we listen to a story our understanding is made by the experience which is provoked in us ‘experiences which are affective, sensual and embodied’ (Good 1994, p.140). He warns that as researchers we must be careful of this,
‘Otherwise, our own projections are likely to dominate our interpretations of others’ experiences of suffering’ (Good, 1994 p.140).

There were several mechanisms set up when planning the research for recording the decisions made in the ‘social trajectory’ through field work. Careful notes were kept each time on the process of negotiating the interview. After the interview I recorded a commentary into the tape recorder about interaction with the participant, how I thought the participants had perceived me and what had been the sub-text of the visit. I recorded my perceptions of their emotional state, the things that they did not talk about and how much I felt what they said was a performance for me as the interviewer. I also recorded my own feelings about the interview, how engaged I had been, how much disturbance I believed that I may have caused in their lives. To complete the picture some reference was made to the general environment in which the interview had taken place.

I myself filled in a questionnaire after each visit (see Appendix). This noted details of any questions that had been asked or advice offered, the participant’s apparent emotional state, how long the entire visit took, the time of day and what hospitality had been offered.

Recruitment

Recruitment to the study was slow and fills agonising pages in my research diaries. The patient participants in the study were recruited via hospital consultants in three separate hospitals. Ethical clearance was obtained in two of these by the project director (Barbara Johnson). People with lung cancer had not been recruited in to the main project. As I wanted to include them as part of my study, I thus obtained support and ethical approval from a further hospital which treated large numbers of people with lung cancer.

Recruitment was in itself a long process. Patients who were said to have been informed of their diagnosis of cancer and fulfilled the study criteria were referred to the study by
participating hospital consultants, thus access was dependent upon the good will of the health professionals. A letter was then sent to the GP informing them of our intent to invite the patient to participate in the study. If no objection was raised a letter was then sent to the person with cancer giving brief details of the research (see Appendix). This was followed by a telephone call a week later, when if acceptable, an appointment was made at the persons home to explain the research in more detail and hopefully record an interview. In order to recruit participants my own study about the families' experiences, the patients were asked at the end of their first interview who was the person who had been most affected by their illness. The participants in this research project were thus chosen by the people with cancer who I interviewed for the main study.

A drawback of this method of recruitment was that participants were defined by the person with cancer - not by themselves. This method of recruitment excluded any whose distress the patient was unaware of, or who would be unacceptable to the rest of the family group i.e. someone that they did not know about or disapproved of or did not trust. Families may well have their own private secrets, traditions and conflicts and these I could never be privy to (Daly 1992).

My means of access to the 'field' meant that it was not possible for me to sample 'on the basis of the evolving theoretical relevance of concepts' (Strauss and Corbin, 1990, p.179), thus breaking one of the 'fundamental canons' (p.178) of the grounded theory method. Once close relatives had been recruited to the study they remained in the research - the interviews were guided by the concepts emerging from the data, but I was unable to sample participants on this basis.

I decided to stop recruitment once I had reached 25 (one further participant referred herself to the study). This was not because I believed that I had reached 'theoretical saturation' (Strauss and Corbin, 1990). Indeed as this was a longitudinal study ending the recruitment of participants did not mean the end of interviewing - there was still a long way to go. This was largely a pragmatic decision. I was becoming saturated in interview transcripts and field notes if nothing else. Furthermore, the themes and issues
arising in the data were beginning to create a reasonably coherent and plausible pattern. A picture was being drawn up of the kinds of feelings and reactions that people might experience depending on the context of the situation. Additional data collection may have made a further contribution, but in this area of research the analysis could never be final. Moreover, on reflection I do have confidence about the findings, and do not believe that including more participants in the study would have changed the essence of what is presented here.

The interviews
All of the people who took part in this study were interviewed in their home. The interviews were conducted on three occasions unless the patient died or the family no longer wished to participate. All first interviews took place 3-4 months after the patient's diagnosis and the second interview 3-4 months later unless otherwise indicated. The third interview was recorded at approximately 13 months. The interviews were undertaken between March 1991 and September 1994, the majority were completed by the autumn of 1992. A few of the third interviews were recorded later as I had to take a 10 month break from interviewing towards the end of data collection. A thank you note was sent after each interview.

In 6 instances interviews were recorded with the bereaved relatives after the patient died. These usually took place quite flexibly approximately 6 months after the death. Contact was made with two letters. A 'condolence' letter was sent as soon as I heard about the death, this was followed a few months later by a further letter and then a phone call. In 6 instances where the patient died a bereavement interview was not recorded with the family. In the cases of 4 participants this was primarily because it had become clear that these interviews were different in nature to those before the death, and the focus of the study was to look at living with cancer and not bereavement. Secondly after a break in interviewing it felt insensitive to make contact again with these families after such a time lapse. A further 2 bereavement interviews were not recorded because relatives were now abroad.
The taped interview usually took 45-90 minutes to complete. A few were longer but I attempted to avoid this because of the difficulties of transcription and analysis. The actual visits to the homes were more lengthy. For example, the first visit lasted between 90 minutes and 6 hours with a mean time of 2 hours and 40 minutes. The mean length of the visit remained about the same over the three interviews, although as a couple of the first interviews were very long, the actual length of most visits increased slightly.

The first interview began by inviting the participant to tell me about their thoughts and experiences from when they first suspected that something might be wrong with their relative (Graham 1984). To tell the story from the very beginning seemed to be the easiest way of getting people to talk for the interview. In the subsequent interviews the participant was asked to speak about what had happened since the last interview and then look at issues or themes which had arisen from the first interview. Finally, ideas identified from other participants' interviews were explored, thus progressively focusing on the themes arising from the whole data set (Hammersley and Atkinson 1995). An aide memoir including issues raised by the individual at their previous interviews as well as the emerging themes was taken to each interview.

I was shown great hospitality by all the participants. The minimum offered was a hot drink. Many of those who knew I had travelled offered lunch if the interview was in the morning. In one family a four course lunch was prepared for my second two visits and another interview was conducted over lunch at a local hotel. Although I was initially advised against this, it felt right to accept the hospitality offered. I was visiting the participants' homes and I was actually asking a great deal from them. As most said they found taking part in the study helpful I did not want to deny their need to reciprocate in some way - and indeed, I enjoyed it.

I completed a questionnaire with the participants at the end of each interview (see Appendix). This recorded demographic details and information about where they saw their sources of support and contact with the health professionals. The questionnaire also included a question about how they were feeling at the end of the interview and
acted as an important part of the debriefing. The findings from this have been woven where relevant into the text, for example, in this chapter in the section describing Demography and in the findings in the section on the Physical manifestation of emotional disturbance in chapter five. The further questionnaire which I filled myself afterwards (see Role of researcher) recorded participants as being tearful or close to tears in all but 7 of the first interviews and only 3 people were recorded as being calm. The debriefing was thus essential.

In spite of this, most of the participants were very positive about the experience of the interview - at the least they saw it as an opportunity to help others. The issues raised by researching experience of a serious illness will be addressed later in the chapter. The research process created a strong bond between myself and the research participants in many cases. I did not record how many times I was hugged and kissed as I left people’s homes but my recollection is that it happened very frequently.

I frequently listened to the interviews on the way home. The interviews were then transcribed verbatim. Initially I did the transcribing myself and later I was helped by someone who was very experienced at transcribing research interviews. All the patient tapes were transcribed by the main project administrator. The participants were offered a copy of the interview transcript to comment on as an early (and as will be shown later fruitless, see section Feminist influence: power, personhood and distance later in this chapter) stage of what Lincoln and Guba (1985) describe as the ‘member check’ which these authors recommend as one of the most crucial techniques for establishing credibility. (Lincoln and Guba 1985).

THE STUDY PARTICIPANTS

Demography
The families who took part in study were distributed over a wide geographic area - from Harwich to Folkestone. A few participants lived in rural areas whilst the majority were urban dwellers. The people who took part in the research were all white - despite those
with lung cancer being recruited from an area of ethnic diversity. About one third of the participants were living quite comfortably, whilst the rest lived in a variety of social conditions and some had very strained financial resources. Four of the relative participants in the study had cancer themselves. Three had been treated before the beginning of the study period and were well. One woman was diagnosed and treated during the course of the research. Two of the spouses of the patients were disabled and thus they themselves required a certain amount of care.

Over two thirds of the participants were women. This reflects the fact that both lung and colo-rectal cancer occur more commonly in men and where the patient was married they indicated that their partner had been most affected by the illness. However, where the patient, male or female, had no partner they universally nominated a female to be interviewed. This is in keeping with the literature on caring which shows there is a predominance of women who are most involved with and affected by those who experience chronic illness (Abbott and Wallace 1990; James 1998). Nevertheless, the study had hoped to research the experience of men and women equally and this issue is further addressed in the section on Gender and caring in chapter six.
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<th><strong>PARTICIPANTS</strong></th>
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<td><strong>Refusals</strong> (excluded from the numbers above)</td>
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19 patients took part, recording 42 interviews

Table 2. Details Of Participants
Participants who took part in this study will be referred to by a research name. For simplicity, a first name only has been used here, although in reality during the research not all the participants were referred to by their first names. Some identifying details have been changed, although if the participants were to read this text they may recognise themselves. Brief details of the participants are included here because their influence and participation in the research process began the moment they were approached to take part.

The following information is taken from the interview, post interview questionnaire/commentary and field notes. Those patients who died during the study are referred to by using the past tense. Otherwise the present tense is used. For clarity, details about the patient will be included first. The participants are described in order of recruitment.

**Brief details about participants**

**Bernard** has advanced colon cancer and was treated with surgery (colostomy), radiotherapy and one year of chemotherapy [three interviews].

**ELIZABETH** aged 41, is Bernard’s sister and lives with her brother and her elderly mother, and works full time in an office. The interviews took place in their large family home which Elizabeth now maintains. She had minimal contact with the health professionals and got her greatest support from a friend at work. Elizabeth was quite emotional during her three interviews which she said she found helpful.

**Karen** had cancer in her bladder and was treated with surgery (urostomy). She died unexpectedly after surgery to change the style of her stoma [two interviews].

**STEPHEN** aged 53, is her husband and father of three adult children. He has a successful career and took 6 months unpaid leave upon hearing Karen’s diagnosis. He was interviewed twice before Karen died, with one very difficult bereavement interview after her death.

**LOUISE**, their daughter is aged 25 when her mother is diagnosed. She is a health professional and lives with friends in a flat in the same city as her parents. She took part
in two interviews - one after her mother’s death.

**ROBERT**, their son is 18 years old when interviewed once (nine months after his mother’s diagnosis) when he was living at home during a year off before university. Robert’s rather unforthcoming interview was his mother’s suggestion. He was travelling abroad when she died.

**Donald** has colon cancer and was treated by surgery with the formation of a stoma which was reversed during the course of the study [three interviews].

**DORIS**, aged 67 is his wife of 40 years and has 2 children and 4 grandchildren, her daughter and family live upstairs. Doris is agoraphobic and as result had little contact with the health professionals. She feels that she has had to give up a lot because of her husband’s illness. Both were interviewed 3 times in their home crammed with the product of Doris’s earlier hobbies.

**Mavis** had cancer of the stomach and was treated with surgery. She was told that she was cured, but was almost continuously unwell and died about a year after the third interview [three interviews].

**MARY**, aged 62 was her sister who is an auxiliary nurse and married with 4 children and 14 grandchildren. Mary is her sister’s key support during the illness, although they did not always see eye to eye. Mary also supports the rest of her family who often seem to be in difficulty. Mary phoned me several times at home when she felt she needed someone to talk to. They both took part in 3 interviews.

**Michael** has cancer of the colon and was treated with surgery [three interviews].

**SAMANTHA**, aged 71 is his wife of 52 years, they have 6 children and Samantha says that she never had time for paid work. They are well supported by their children, but have led a financially impoverished life. During the study where they both took part in 3 interviews Samantha herself developed a brain tumour for which she had surgery and recovered well. Nevertheless her subsequent interviews became more about her own illness than her husband’s. Despite this Samantha puts many of their problems down to old age rather than cancer.
Maurice had colon cancer for which he was treated with surgery. He lived in sheltered accommodation and died in a hospice [two interviews].

BETTY, aged 46 is one of his 4 children who Maurice said gave him the most support. Betty is married with two children and works part time as a healthcare professional. She has an interesting, attractive home but herself had suffered back and head problems during the study period which had not been fully diagnosed. Betty completed three interviews - one after her father’s death. She is very unhappy with much of the professional care he received.

George has lung cancer and was treated with 6 courses of chemotherapy and radiotherapy [three interviews].

GEORGINA, aged 65 has been married to George for 42 years and has one son. The interviews took place in their small flat which has a beautiful garden - their pride and joy. Georgina is totally devoted to her husband with few other close contacts. She accidentally broke both of her wrists during the study period but would not contemplate any outside help.

Jeremy has lung cancer with limited disease and was treated by surgery. Jeremy was interviewed once only because he was unable to acknowledge his diagnosis to me [one interview].

JANE, aged 31 is Jeremy’s daughter, she is married with 2 children and over the course of the interviews goes back to working part time as a secretary. Jane also finds it difficult to talk about cancer and much of the first interview is about her own post natal depression. Just before the second interview her sister-in-law died suddenly from leukaemia and much of the second interview was about this and her concern about her husband’s distress. In the third interview - three years after the first, she reports life pretty much back to normal.

Jack had lung cancer and was treated by surgery. Although he was told he was cured he remained very anxious and died about 10 months after his first interview [two
interviews].

JILL, aged 58 was Jack’s long term landlady living in a fairly small local authority flat. Her husband had died of cancer when her two children were young. Jill looks after her grandchild and also gave up much of her social contact to care for Jack as he became increasingly debilitated. Jill took part in three interviews, one after Jack had died. Her interviews are peppered with reference to the other sad events in her life.

Anthony has lung cancer and was treated with surgery. Despite being told he had been cured he remained very anxious [two interviews].

ANNE, aged 66 is his wife of 46 years. They have 2 children and Anne used to work in tailoring. They are both quite disgruntled about their housing and local environment. Anthony’s anxiety restricts Anne’s lifestyle considerably and he even listens in on her interviews. They (apparently led by Anthony) do not think that it is a good idea to keep going over the illness and therefore only wished to take part in two interviews.

Julian had lung cancer and was eventually treated with radiotherapy. Julian was not interviewed for the study as he was quite poorly and highly protected by his daughters. He subsequently died.

JULIA, aged 59 was his wife. They had been married for 40 years and had 6 children. Julia herself was very unwell, house bound with cardiac failure and a history of mental illness. She had been very dependent on her husband. Her interview which she initially refused was short and centred largely around her own health problems although she did seem to understand quite clearly that her husband was terminally ill.

JUDITH, aged 38 is one of their daughters. She is divorced with 2 children and works part time as a cleaner. Judith’s life revolves around caring for her parents - she does most of the practical work because neither of them like outsiders. She had been very distressed about the way the professional carers had treated her father.

JADE, is Judith’s elder sister and she has a very supportive relationship with Judith, working closely with her to care for their parents. Jade is married with two children. Her mother-in-law had also recently been diagnosed with cancer and her father-in-law’s response to this had been to commit suicide, thus devastating Jade’s husband. This was
the longest interview in the study and the visit took 6 hours. Much of the interview was taken up with her family’s multiplicity of problems.

This family was interviewed once only. Julia was not keen on a second interview and because of my own circumstances I was then unable to get back to Judith and Jade until over a year after Julian’s death. To request an interview then seemed potentially insensitive and out of keeping with the way the study had evolved.

Arthur had cancer of the lung with limited disease and was treated with chemotherapy and radiotherapy. He was quite unwell and suffered a stroke during treatment. Arthur died suddenly the day after his second interview [two interviews].

Andrea, is 47 and had been married to Arthur for 26 years, they had 2 adult children. Andrea works as a company director and they live in a beautiful old farmhouse. Arthur was extremely depressed about his illness and Andrea did her utmost to support him and raise his spirits. Andrea was interviewed twice, once before and once after her husband’s death.

Jonathan had cancer of the lung and was treated with radiotherapy. He was very poorly when interviewed and died from a pulmonary haemorrhage at home two months later [one interview].

Jackie, aged 45 had been married to Jonathan for 9 years, and has 3 children from her first marriage. Both she and Jonathan are ‘Born again Christians’, Jackie works part time and gave this up to care for her husband. Jonathan received only minimal support from the health care professionals and in the event Jackie felt very unprepared for his traumatic death. Jackie completed 2 interviews one before and one after Jonathan’s death.

Monica has kidney cancer and was not told her diagnosis until 6 weeks after her treatment with surgery [two interviews].

Melvin, aged 68 has been married to Monica for 43 years and they have one daughter in her 40’s who lives with them and who they have not told about the cancer. Melvin is
devoted to Monica and appeared very distressed during the interviews, but as he and
Monica had agreed not to talk about the illness he was unable to express this. This
couple both completed two interviews but felt that after this they had said enough and
did not want to undertake a third one.

Daniel has bowel cancer which was treated with surgery and the formation of a
permanent colostomy [three interviews].

DOREEN, aged 56 has been married to Daniel for 33 years. She is very involved in
voluntary work, particularly as they have a handicapped daughter. Doreen herself had a
brain tumour 3 years ago for which she had surgery and made a good recovery. Her
mother died from cancer shortly before Daniel was diagnosed and Doreen remains very
distressed about this. This couple are very sociable and well supported by friends,
although the cancer has caused some rifts within the family network. They make light
of the illness although there does appear to be an underlying anxiety and it has resulted
in them making various structural changes to their life for example moving in to separate
bedrooms. Doreen completed 3 interviews.

Peter has testicular cancer and was treated with surgery [not interviewed].

DEBRA, aged 25 has been married to Peter for 5 years and she has 2 small children.
Peter was interviewed 3 times by my colleague and Debra actually asked if she too could
be interviewed and was thus referred to this study. Debra was pregnant when Peter was
diagnosed and subsequently miscarried. Debra was very distressed about her husband
initially but his subsequent recovery and good health meant that their life was pretty
much back to normal by her third interview exactly 2 years later.

Nora has colon cancer and was treated with surgery and radiotherapy[three interviews].

GEOFFREY, her husband is 71 years old and they have been married for 48 years and
have one son. Geoffrey himself suffers a brain condition which affects his sight. Nora
has cared for him for years. Nora highly protects Geoffrey from concern about her
illness, nevertheless he does have a great underlying anxiety because without his wife he
himself would need full time care. Geoffrey’s condition means that without support this
makes places such as hospitals very frightening for him. This couple are very hospitable and well supported by their local community. Geoffrey was interviewed 3 times.

Isabel has cancer of the colon for which she was treated with surgery and a year of chemotherapy [three interviews].

IVAN, is a 46 year old transport worker and has been married to Isabel for 22 years, they have 2 sons. Ivan himself had a melanoma, diagnosed 6 years ago. Ivan has found Isabel’s cancer has been very much more difficult to deal with than his own. They both feel that the cancer has affected their relationship and Ivan feels very unclear about where his own life is now going. Ivan has very little contact with the professionals looking after his wife. He was interviewed 3 times in their cottage, the third interview being two years after the first.

Theresa had lung cancer and was treated with 4 courses of chemotherapy which was discontinued because of intolerable side effects. Since then she had experienced many distressing symptoms of the disease and subsequently died [one interview].

TERENCE, aged 71 is a retired docker and had been married for 49 years with 2 children and 3 grandchildren. He himself had had cancer and was treated with surgery and the formation of a colostomy. He again had found his wife’s illness much more distressing than his own and it had a considerable effect on his health. This couple were interviewed once only. A bereavement interview was not undertaken because I felt unsafe with Terence on my own following an incident at the first interview.

Norma had lung cancer and was treated with chemotherapy, she died 6 months after the first interview [one interview].

NORMAN, her second husband, is aged 70 and a retired successful business man. It was difficult to secure an interview with this couple because of Norma’s failing health and her family’s protection of this. The one joint interview which did take place was recorded at a local restaurant over lunch where my presence made them confident enough to fulfil a wish of Norma’s to go out. Contact was maintained with this couple by telephone but a second interview did not take place as Norma was very poorly for
several months before she died. Norman went abroad for a while after her death and a bereavement interview did not take place.

June had cancer of the lung and was treated with chemotherapy. We kept in contact, but my own circumstances meant that I was unable to complete a second interview before she died [one interview].

Rose, aged 46 is her daughter who lives in the southern hemisphere and is married with one son. Rose came over to England to stay with her mother for a couple of months. This was a one off interview because Rose had to return home, Rose's greatest problem being the distance she lived from her mother. Rose made huge efforts to nurture her mother's failing health, but found her depression very difficult to deal with. They were well supported by the local community.

Alison, aged 40 had heard about the study and asked to take part. Alison's interview was a pilot for a possible further stage of this research which would include 'expert relatives' - those who had gone through the experience of being the relative of somebody with cancer and had time to reflect on how it had affected them. This was not pursued, partly because in bereavement or cure, the relatives are telling the story from a very different perspective where there has been an ending of sorts. Nevertheless, Alison's interview is included in the analysis because her experience makes an important contribution to the study. Alison is married with one daughter and works full time. Her mother, with whom she had a difficult relationship, died from breast cancer after a protracted illness.

Feminist Influence: Power, Personhood and Distance

It is important to acknowledge that the process of this research was influenced by several factors, in particular my relationship with the participants and the implications of undertaking this kind of work for both the researcher and those researched. This is discussed in more detail below; first by looking how among other things feminist research writing clarified the contribution that my own background and social
circumstances made to the data being collected, and second by addressing the implications of research which involves the experience of serious illness.

The research interviews were influenced very early on by the work of feminist researchers (Roberts 1981; Webb 1984). Writings on feminist research methods articulated several of the misgivings which I had experienced in the first interviews where there were many inconsistencies between what I planned to do and what was actually happening. A major discomfort with the initial research methods was the feeling of intruding upon someone’s already difficult life, asking them to recount their experiences to order for my tape recorder, hearing their distress, then thanking them and leaving.

I was therefore constantly surprised that despite my feelings of awkwardness and guilt, many of the participants were extremely generous with their time and hospitality some seeming genuinely grateful for the opportunity to take part in the research. This tended to make me feel even more uncomfortable about my (initially) carefully maintained ‘distance’.

Oakley (1981) writes “personal involvement is more than dangerous bias -it is the condition under which people come to know each other and admit others into their lives” (Oakley 1981, p.58). My research into the experiences of the relatives and friends of people with cancer required personal involvement between myself and those who took part in the study. I was proposing to visit people’s houses six times or more and ask them to relate to me the most intimate aspects of their lives which on several occasions they had not shared with anyone else. Acknowledging this involvement and moving my stance away from that of the neutral, passive researcher made carrying out this research possible for me. It felt much more ‘normal’ to create a more reciprocal relationship with the participants and to share some of my own experience with them. Not to do so produced strong feelings of guilt and loss of self. Measor describes the process of critically and rationally examining a set of practices which she had developed intuitively and without methodological rigour (Measor 1985). Similarly I began to feel that I could
'come out' methodologically about the covert and intuitive practices I had been using not only in this study but also in my previous research efforts.

My concern that the research relationship be reciprocal was particularly pertinent in a situation where the respondents are living close to someone with cancer and the researcher is a cancer nurse. A standard information sheet from Cancer Relief Macmillan Fund; 'Help is There', detailing national contacts for people with cancer, although frequently accepted, did not inspire much interest. Both Webb and Oakley describe how the women who participated in their studies asked them for information about their respective conditions, surgical hysterectomy and motherhood. Both felt that their research was enriched by deciding to respond to these requests and record this as part of the research data (Oakley 1981; Webb 1984).

"Feminist research capitalises on the personhood of the researcher, who uses her feelings and experience to guide her research" (Webb, 1984. p.250). In Webb's view honesty comprises an important element of rigour. In this research I decided that as far as I was able, and in the knowledge that I had no access to medical records, I would answer questions and give advice where I felt that I had the understanding to do this. If this was not recorded on the taped interview then I noted this on the post interview commentary or questionnaire. I was obviously concerned not to mislead or misinform people, however, my own 'personhood' included having spent five years working part time at a national cancer information service (Cancer Bacup) where one had no medical details of the callers, most of whom were family and friends. I thus felt reasonably confident.

Nonetheless, having made this decision I was still confronted by dilemmas. The participants in this research did not present me with neat questions about side effects of treatment. On occasion I felt my face being searched for agreement as I was being told that they believed that their relative was going to be cured. Twice I was asked outright how long I thought that their relative had to live. This was easier to deal with as obviously I did not know. It was harder to hear accounts of poor care or mismanagement by the professionals. A few of the participants did have expectations of
me ‘to get things done’, usually practical things such as grants or aids at home. One hour after an interview where Anthony complained bitterly about the state of the lifts in the block where they lived, a man came to clean them. On my next visit I was told that this minor miracle had been attributed to me!

I believed that the home setting for this research was important because it was the experience at home which I was studying and hopefully meeting people on their home territory might make them feel more at ease. I attempted to give participants as much control over the interview process as they wanted. I showed how the tape recorder worked. However, on the few occasions that the tape recorder was turned off I think the participants were too deeply involved in their story to think about which switch to press themselves. In the end I also realised that it was actually better to leave the tape running, despite my misgivings about recording distress for a research study. To turn the tape off was to interrupt the story and seemed to imply that it was not acceptable to be upset. It was thus turned off only four times during the study.

I had initially hoped that giving a copy of the transcript might provide not only respondent validation but also offer the relatives a greater degree of participation in the study. In this research only one of the relative participants wanted a copy of their transcript and this lack of interest coupled with my own concerns about how they might feel rereading their distressing stories sometime later, meant that the offer was made in an increasingly low key way, more ‘its there if you want it’. Instead I used the subsequent interviews to check out with the relatives if I had grasped the sense of what they had said in their earlier interviews. As Koch and Harrington who both experienced problems in returning transcripts to participants in their respective studies comment, the taping and accurate transcription of the interviews ensured at least verbal accuracy (Koch and Harrington 1998).

Although I would describe myself as personally espousing many feminist values, this research was not underpinned by feminist epistemology. Thus the research was not in essence focusing on the power relations between the men and women, nor was this
research intended to be useful only for women. However, my experience as a woman was undoubtedly central to my involvement in this research process. As Allen (1998) comments;

"Feminist research that is reflexive emphasises the researcher's awareness and use of her own experience of the research process as a woman" (Allen 1997, p. 456)

The participants in the research responded to me as a woman in my thirties and different data may have been produced if I was a man. Like Allen (1998) I used feminist research methodology to include men in the study. The values of reciprocity and involvement in the research process are not incompatible with being male. Nevertheless, Reinharz (1992) discussing mixed gender field sites writes;

‘feminist ethnographers must always be prepared to deal with the intersection of their behaviour and the gender ideology of the setting they are studying’ (Reinharz 1992, p.62).

In this study, where I was not interviewing men in the safe 'environs' of the hospital clinic, the interviews led me to question some aspects of the research method. Without assuming the vestiges of authority that a more positivist research approach might carry, a researcher on unfamiliar territory can be quite vulnerable (Webb 1993). Some people have expectations of a researcher arriving 'armed' with a questionnaire. When this expectation is not met, a new view of the researcher has to be constructed by participants.

I felt uncomfortable at times interviewing some of the men who took part in this study and it might have been easier with a more distancing interviewing manner. I felt socially ill at ease interviewing one of the younger male participants when we were alone together in the house. Another husband who I interviewed on his own made to grab at me and give me a kiss. This was an unnerving experience which happened before the interview commenced. Such was my drive to collect data, and also judging
that I could control the situation, I carried on and conducted the interview. But this was in the most brusque controlling formal manner that I could muster.

Other uncomfortable interviews might have been caused by the research approach rather than merely the fact that the participant was a man. Geoffrey became quite angry at me during his first interview. This made me feel very awkward and I found it difficult to understand. Geoffrey insisted that he was not affected by his wife's illness and so had nothing to say about it. On reflection I realised that his own ill health made him extremely vulnerable to his wife's well-being. Nora had carefully protected him from the implications of her illness and I had been asking him to talk about something he himself had not really addressed.

Furthermore, I always felt that however close I became to some of the participants and whatever difficult times I experienced personally during the data collection I was still the one who came with the tape recorder and it was their stories which were contributing to my academic achievement (Webb, 1993). I was not living with someone with cancer. In this there could be no equality.

Cornwell (1984), who did the interviewing for her study of health and illness in East London in an area close to where some of my interviewing took place, comments that sisterhood could not be relied upon to break all social barriers. She discusses the great social divide between the academic researcher and the research participants. She was also, like me, trying to use feminist influenced research methods to interview men. Cornwell describes the scenarios in some of her first interactions with the research participants; the polite responses and obvious attempts to make a good impression. Cornwell described her early interactions with the participants as the 'public accounts' referring to Goffman's discussion of 'managing appearances' (Goffman 1959)

One of my most stilted encounters was with a patient named Jack who sublet a room in a council flat. The whole interview was actually quite bizarre as we sat in a rather scruffy room with Jack wearing his three piece suit with tie, gold cufflinks and very shiny shoes.
Jack obviously found it quite difficult to speak on tape and said afterwards that he wished that he had had a drink first. I felt that he had left most of the things that I wanted to hear about out of the interview. This was very much a ‘public’ account, put on for my benefit.

However, worse was to come. Jack had been quite reluctant that I should interview the woman he shared the flat with - and as I realised later this must have been because she contradicted much of what he had told me about himself. At the first interview, Jack had told me about a big wedding that he had been invited to, with a large marquee and hundreds of guests. When I returned to interview Jill, his landlady, I asked him if he had enjoyed this event. In response he denied all knowledge of the wedding. Jill laughed and said that they did not know the sort of people who would have a marquee. I hurriedly pretended that I had got him confused with another participant. This served as a painful reminder to me both about issues of confidentiality and also about my lack of reflection on the incongruence between what Jack had been telling me and what sense I could make from what I saw.

As Goffman has indicated, with greater information and understanding of the situation, less emphasis needs to be placed on the impression made (Goffman 1959). On my second interview with Jack he was much more relaxed in his jumper and trainers.

In Cornwell’s study, the ‘private accounts’ came as she got to know people better and frequently this was when they began to relate stories rather than when answering direct questions. In this research there were, I would claim, relatively few incidents of ‘public accounts’. This was perhaps because the methodology required story-telling right from the beginning and issues about the illness were uppermost in most participants’ minds. Having said that, these accounts were always, being given to a new acquaintance with a tape recorder running! Many were quite self conscious initially, although most had overcome this by the second interview. The difficulty for most relatives was to be able to talk about themselves rather than the patient and many also told stories about other difficult times in their lives.
Furthermore, there were participants in this study where the social divide between researcher and participant appeared unbridgeable. One of the women I found hardest to interview felt, I judged, few points of contact with me. Samantha was very poor (she had brought up six children in a one bedroom flat) and her husband could not read. I was quite outside her usual social milieu, however I presented myself. It took until the third interview for her to relate her private story to me. This account of her son’s mental illness and skirmishes with the police helped put the other interviews in context. However, for a variety of reasons - most importantly her own ill health - we still did not ever get around to really talking about what was on my research agenda, that is her husband’s cancer.

Indeed, however much I stated my aim of sharing the interview there was still an occasional feeling of ‘losing’ control of the situation and believing that in order to obtain useful data I should be more firmly imposing my agenda. I felt some participants were taking me down side tracks which I really did not feel were any of my business. For example Jane talked on tape for nearly 40 minutes about her post natal depression. Jade talked for two ninety minute tapes about all the difficult life experiences over the previous two years, only a small part of which related to her father’s cancer. Scheurich (1992) describes how “Interviewees do not simply go along with the researcher’s program.... they carve out space of their own, ..they can often control some or part of the interview.” (Scheurich 1992, p.14) . He challenges the desire of researchers to empower the interviewee as itself ‘hierarchical’, and based on the presumption that the researcher has all the power in the first place. Describing the concept of resistance Scheurich points out how participants in research studies may use this opportunity for their own platform and to fulfil their own needs.

This was the case at times in this study. Indeed, the instances when I became really anxious and frustrated about where we were going, even considering not transcribing sections of the interviews, were often the times when the participants seemed to be taking control. However, they were not necessarily so much resisting the research,
rather by explaining their experience more fully, they were putting it in context. The set of experiences of living with someone with cancer is partly made up from the other experiences which form their context. Thus it is impossible to begin to understand what it is like to be close to someone who has cancer without knowing about, and considering these other factors. For example, that the relative is suffering from post natal depression, or that they are recently bereaved, or that their partner is depressed.

Several of the arguments used by feminist researchers, the need for involvement and reciprocity may be found in the work of Reason and Rowan (Reason and Rowan 1981) and in the language of collaborative inquiry. This work has recently been influential on other research projects that I have been working on (Krishnasamy and Plant 1998). Nevertheless, at the time when I was doing my first anxious data collection it was the feminist writers which were more accessible and in tune with my own experience

**IMPLICATIONS OF RESEARCHING SERIOUS ILLNESS**

It was paramount during the process of this research that the individual’s resources marshalled for living with a diagnosis of cancer in a close family member should not be disturbed. I was conscious throughout interviewing that taking part in this research could have a disturbing effect on the participant’s equilibrium. Daly (1992) comments that researchers may actively encourage informants not to talk about issues that may be distressing (Daly 1992). One of the purposes of this research on the other hand was to find out about what had often been the most distressing experiences in a person’s life.

That this was a study about a life-threatening illness has had important implications for the way that the research was carried out. There is a growing debate, about undertaking research to study human experience in distressing situations (Renzetti and Lee 1993). This is particularly pertinent where the research is of a qualitative nature “sometimes evoking strong emotional responses and sometimes pursuing thoughts that might otherwise never be revealed,” (Cowles 1988, p. 163).
De Raeve (1992), has questioned whether it is ethical to undertake research with patients receiving palliative care at all, pointing out that any potential benefits may merely be filling a vacuum which should be the domain of the health carers. (de Raeve 1992). Eardley et al (1991), reviewing the literature on ethical issues in psycho-social research with patients with cancer, were more positive about the benefits accrued by participating in a research programme. They suggest that excluding patients who are keen to participate in research and who understand its implications is a “diminution of the patient’s autonomy” and, where the research is well designed, patients should be allowed the sense of achievement of expressing views on issues which may well be very important to them. Eardley and colleagues identified two key issues for concern; that of obtaining informed consent and also the need to monitor the impact of the research process on vulnerable subjects (Eardley et al. 1991).

**Informed Consent**

There were two problems in gaining informed consent from the participants in this research. The first problem has been addressed by several authors and concerns the difficulty of fully informing the participants of the potential risks and benefits of taking part in research, when at the outset the flexible nature of the research means one is unable to predict exactly what the participant is going to say and thus know in advance what effect this process will have on them (Larossa et al. 1981; Ramos 1989; Ford and Reutter 1990; Holloway 1992). Larossa et al (1981), suggest that this is a particular problem when undertaking qualitative family research, where interviewing various family members in their own home might create a situation in which the participants revealed more about their relationships than they had initially planned. Self-revelation may also potentially have profound effects upon the individual. In this research I dealt with this initially by a careful negotiation of each interview, explaining in detail what the participants would be expected to do and emphasising that they could discontinue the interview at any moment (described in Rosenblatt (1995) as ‘processual consent’). I discussed the impact of the interview with the participants after each visit. I made it clear that the interviews were absolutely confidential for each individual.
I wanted to make it easy for people to refuse to take part. However, in practice it must have been difficult to send me away once I had turned up on the doorstep. Only one person refused to participate under these circumstances and this was because the patient was very ill. Nonetheless two couples did refuse to undergo the third interview. In both these instances it was the patient who wanted to discontinue taking part in the research and I was unable to interview the relative alone. One of the particular problems with consent in this study was that the process of access meant that I had to first ask the person with cancer’s permission for their relatives to take part. On the other hand it is possible that in some cases a relative may not have wished to take part, but did so out of loyalty to the patient (Ford and Ruetter, 1990).

I hoped however to avoid some of the problems concerning informed consent detailed by Smith (1992). She cautions against any kind of manipulation in order to gain consent to participate. An example of this manipulation is the possibility that some people participate in research studies because they believe that this will benefit their medical care (Smith 1992). I had believed that because I came from the university and not the hospital I might be exempt from this. However, the introductory letter to the patients mentioned their hospital consultant’s name (see Appendix). Having once made this connection it is possible some people may have felt too vulnerable to refuse my first request to pay them a visit to explain the study. With the family interviews I did endeavour not to pressurise potential participants by giving them time to think about their response to my request. If the relative was not there at the time, I wrote to them first, following this with a telephone call about a week later.

The second issue with informed consent concerned the deep fears engendered by cancer itself, both for those treating and giving information about it as well as for the patients and their relatives. Criteria for inclusion in the main project stated that the patient should be fully informed of their diagnosis with the implicit assumption that they acknowledged this, both to themselves and others. On the consultant’s consent form, the words used by the doctor to describe the patient’s diagnosis were requested (see Appendix). Initially these same words, for example ‘cancer’, ‘tumour’, or ‘malignant’,
were used in the letter of contact to the patient explaining the study and asking if a researcher could come to visit them.

These early letters caused some very serious problems for the main project; one was read by a relative who did not know that her father had cancer; another because of an administrative error, informed a woman that she had cancer when in fact she did not; the third referred to a woman’s malignant disease (the words used by the consultant) which she interpreted as meaning that her cancer had spread throughout her body (Johnson and Plant 1996).

Reflection on these harmful incidents led to a change in the process of gaining access and obtaining informed consent. The letter was altered so that it introduced a research project looking at what help and support was needed after a stay in hospital (see Appendix). The revised method required that at the first encounter the person with cancer should - as part of the process - tell the researcher what they believed their diagnosis to be. Only following this, could the researcher ask them to consent to take part in a study about the needs of people with cancer, thus avoiding disruption to those who may be coping by ‘denial’ (Greer 1988) or any administrative misunderstanding.

I conducted two interviews with patients who did not acknowledge to me that they had been told that they had cancer. These interviews were thus focused around what help and support they might need after being in hospital. For one of these patients, I felt that to speak with his son who lived with him might become deceitful. Jeremy on the other hand thought it a good idea that I contacted his daughter who supported him daily.

Jane, Jeremy’s daughter, took part in three interviews. She told about how her father collapsed when he was initially told his diagnosis and thence forward never mentioned it. Furthermore Jeremy had been admitted for psychiatric treatment a couple of months after my visit with him. If I had asked either of these men outright for consent to participate in a project looking at the needs of people diagnosed with cancer it could have been a deeply disturbing experience. This concern is also relevant to studies using
more quantitative methods to collect data, which invariably assume that those completing questionnaires will have acknowledged their diagnosis.

Similar strategies were used when obtaining consent for the interview with the relative. I waited for them to talk about the illness and tell me what they knew first, although in reality I had often ascertained some of their perception of the situation before I approached them for consent. All of the relatives acknowledged the diagnosis.

Impact of Interview - Monitoring and Safeguarding

A further concern raised by Eardley et al (1991) is monitoring of the impact of participation in the research. The questionnaire at the end of each interview asked participants a direct question about how they felt after taking part in the research. Concerns about monitoring distress, however, should mean more than merely recording it and several other precautions were built into the methods to attempt to contain distress.

The interviews in this study required participants to think back over painful experiences. However sensitive I attempted to be, this was at times difficult. Melvin sat with tears pouring down his cheeks during his first interview. He would not allow these tears to be acknowledged. I attempted to keep the interview on safe ground but it was difficult to know where to find it. Debra was so relieved about her husband's health by the second interview that she felt sure she had nothing more to say to me. However, as she began to recall the events of the previous few months which she believed she had put behind her, she became more and more emotional and eventually completely broke down and left the room. On recovery she reassured me that this was probably good for her, however she also admitted that the first interview had had some effect on her. I felt that she should stop taking part in the research. However she would not hear of it because she believed what I was doing was so important. Doreen who had also not anticipated feeling upset by the interview, indicated that her distress was because she had found herself talking about the death of her mother from cancer instead of about the illness of her husband as she had expected.
In an attempt perhaps more to reassure myself than to confer any benefit on the participants, I always left my home phone number after the interview with the message that they could ring me at any time if they wanted to talk over things thrown up by the interview. In practice nobody ever took me up on this offer, although people did ring or write to give other bits of news and information.

The research was designed so that the timing of the interviews would be at the less obviously stressful times in the career of the illness. The aim of this research was not to record the times of crisis, but living with everyday experiences. Thus the first interview was at three months and after the initial diagnosis period (Weisman and Worden 1976). The interviews were also negotiated with participants so that it would be an appropriate time in their life to take part in the research. This was particularly difficult in the case of the interviews which I arranged after the person with cancer had died. I planned to interview them three to six months after the death and the first period of raw grief. Indeed Jackie who I interviewed six months after her bereavement said that she would have been unable to take part in the study again until this period had elapsed. However, in the letter written to bereaved relatives I indicated that I would go to interview them as soon as they felt ready. I interviewed Stephen two months after his wife’s death because he requested it. However, during this interview I wondered why I was sitting and taping such desperation when I was not even sure it would be useful for the research.

Cowles discusses the timing of interviews, not only how frequently they should occur but also how long they should be (Cowles 1988). She initially set a time limit of 90 minutes for her interview visits, believing this would be flexible but also putting a limit on interview fatigue. I did not set any limit on the amount of time which I spent in a participant’s house in this study, although the interview itself usually took between 45 - 90 minutes. The whole process could take much longer. I was concerned about fatigue, but believed that most people need to complete their story and were likely to feel less disturbed after I have left if they have been able to tell their whole story in a ‘natural’ time scale.
The confidential nature of the research also meant that it was not straightforward to inform other professionals of any of the difficulties raised during the interview, for example if someone was ill-informed or very distressed. One interview with Karen, a patient participant, left me very worried (she mentioned suicide) and after much deliberation I later telephoned her back to ask her permission to arrange some professional help. In the event Karen did not want me to do this, but after this incident I resolved to address issues of concern as they arose, before leaving the participant’s home. Fortunately, this issue did not arise again.

**Benefits and Drawbacks for Participants**

Despite the concern about disturbing the participants in the study, one of the most salient findings of this research project is how beneficial many of the people regarded the opportunity to talk and what little chance they otherwise had. In analysing what might help the relatives of people with cancer, some of the answers were found in the interview process itself. When asked about the impact of taking part in the research the responses were largely positive. At her first interview Elizabeth started to cry and explained:

"It's actually the first time I've talked to anyone".
[Elizabeth 1 p.3]

After her third interview, over a year after her brother’s diagnosis, when I asked her to comment on the effect that the interviews had had on her she said:

"I cried the last two times and I think it does you good. Afterwards you feel better that you've let the emotion out because somewhere that's been bottled up...I think...you need to do it".
[Elizabeth 3 p.35]

Several of the participants described the interviews as ‘therapy’; some said that they were helpful or that they did them ‘good’. Stephen commented after his difficult third interview:
“it does help me an awful lot...it helped me...both Karen and I...very much...when you interviewed us each before, and we both agreed it did help, much more so than any official stuff that we've had. And... it is nice to be able to talk to somebody who is unconnected with family, and unconnected with friends...on things like this, which as I say I honestly don't think I could talk to anybody about...because some of the things are, to me, strange, and therefore I think it would be very strange to anybody that hasn't had anything to do with it, and even maybe to people who have, because I would think these things affect different people in very different ways.”

[Stephen 3 p.24]

I was particularly concerned about the participants who said that they coped by not talking and thinking about the illness and its implications. At her first interview Jill told how she coped by putting her head in the sand. I asked how she was feeling at the end of her third interview:

“I feel fine, yes, I do... honest. Sometimes its better talking it out, more so with a friend [H.P.]...your own you can't say, cos you upset them or whatever... and... sometimes its better to talk it out with someone else I think.”

[Jill, 3, p.22]

Betty commented at the end of her first interview, “at least it gave me a chance” [post interview questionnaire]. I asked Andrea if it would have been helpful to talk to someone after her husband died and she replied:

“I think sometimes... like I talk to you... or like we've talked to you before... often... maybe its a good thing to talk to an outsider someone outside the family, because often you can get out of your body and your system, thoughts which you cannot always express to your family.”

[Andrea, 2 p.29]

For some, the interviews allowed a catharsis and the opportunity to voice fears without feeling judged. Being attentively listened to may be very helpful in itself, and this may have been facilitated because the participants believed that they were talking about themselves in order to help someone else, the so-called ‘helper-therapy principle’ (Reissman 1976). Rosenblatt comments that he is not surprised when he is told that that
an interview about loss has been therapeutic, because of the integration, crystallisation, naming and the healing that comes with the story form' (Rosenblatt 1995, p.150). Nevertheless, the participants almost universally rejected the idea of a counsellor. They were suspicious of this role and this was compounded by the fact that they themselves were not ill.

Daly (1992) comments that when it comes to talking about personal issues some people are much more comfortable talking to a stranger with whom there is little possibility of future interaction. Daly (1992) quotes Simmel’s (1950) discussion of how these relationships may take on the character of a confessional and recommends wherever possible to maintain a degree of the distance and mystery of a stranger in order to encourage a full account of the participant's experience (Daly 1992). Whilst I was always an outsider to those who took part in this study, those who became less distant during the course of the visits nevertheless did not seem less likely to talk in depth about themselves.

There are however potentially serious drawbacks with this sort of research relationship. There is no therapeutic contract with the participant. So, whilst talking might temporarily offer some relief, something may be started that could then remain unfinished. Daly (1992) finds that because of the often intimate nature of qualitative family research there is great potential to confuse the researcher role with a therapeutic role. Offering an outlet and then withdrawing this could be quite harmful (Larossa et al, 1981, de Reave, 1992). During the later interviews I was able to discuss these issues with participants and they did appear to be clear about the frequency of the visits and the boundaries of the research process.

As well as the experience as a cancer nurse, I have some training in counselling. Rosenblatt (1995) believes that it is unrealistic to expect to draw a clear boundary around what is 'therapy' and what is not. He comments that as a researcher who is talking to people about loss and grief:
"I must have the therapist's skills in listening, acknowledging, avoiding being judgmental, bracketing personal reactions, supporting, knowing when to back off, and realising that something has been misunderstood" (Rosenblatt, 1995, p.149)

Coyle and Wright (1996) question whether researchers should approach sensitive issues without being equipped to deal with the resulting distress. They believe that using the 'counselling interview', creating a supportive, beneficial relationship with research participants, will also serve a research function by encouraging people to elaborate their experiences (Coyle and Wright 1996). My previous experience in working with distressed people may have enabled me to obtain richer data and perhaps also did offer them some support, however on the other hand this could also be regarded as exploiting vulnerable people in order to further my own research career.

In her paper 'Can there be a feminist ethnography?' Stacey (1988) points out;

"Precisely because ethnographic research depends upon human relationship, engagement, and attachment, it places research subjects at grave risk of manipulation and betrayal by the ethnographer" (p.22-23).

Because of the close relationship created by the research it becomes harder for the participant to refuse to take part, the more intimate the data, the more vulnerable are participants to its misuse. Some, I am sure, would have preferred it if I had asked them to fill in a questionnaire. Stacey concludes "rigorous self-awareness of the ethical pitfalls in the method enables one to monitor and then to mitigate some of the dangers to which ethnographers expose their informants" (Stacey 1988, p.26).

During the process of carrying out this research I have consistently attempted to look for any potential dangers caused by the research. Nevertheless, I remain concerned that I was not aware of all the potential areas of distress. The fact that these two couples felt comfortable to leave the research is reassuring, but I have no guarantee that there were not others who were too polite to tell me to go away.
Confidentiality

A further area of sensitivity in the collection and analysis of qualitative data is that of confidentiality. In reporting these data naturally the participants' names and other details have been changed. Nevertheless as there are only a small number of participants in this study and I have interviewed them in depth on several occasions, some of their details might be recognisable to those who know them (Ramos, 1989). Larossa identifies two major risks under these circumstances, that of public exposure and self-exposure (Larossa et al. 1981).

Public exposure could occur as a result of publication of the research findings. Although it is unlikely that many people will read the thesis journal articles are more accessible. These could be read by the professionals attending the patient or by other family and friends who work as health professionals or academics. Becker's suggestion of an assessment of each individual situation for the potential to cause suffering seems sensible (Becker 1964). On this occasion the time lapse between data collection and publication may appear to be an advantage.

Larossa and colleagues (1981) described self-exposure as the exposure of a family to itself. This could cause harm where a family situation is recognised, particularly where individual's interviews are confidential and some participants say things which they have not shared with anyone else. Self recognition could in itself be a problem for some. The research interview takes place under a particular set of circumstances and despite giving consent an individual might later feel uncomfortable reading their words. In addition, when the interviews take place it is not possible to predict what the analysis of the whole data set is going to show. This issue remains a worry which I have been conscious of whilst writing. I have endeavoured to deal with this by representing the participants as sensitively and respectfully as possible without avoiding the sometimes difficult implications of what has been said.

Furthermore, I have also occasionally felt as if I was being used as a communication channel between couples where the safety of my presence was used to say difficult
things. Andrea sat in for the whole of her husband’s second interview (which afterwards I was very relieved about because he died unexpectedly the next day). My field notes at the time said that I believed I was providing an environment which seemed to be facilitating a dialogue between them about two issues in particular. (The first being the different ways in which they coped with the disease, and the second that Andrea wanted Arthur to have more interest in life and take more exercise because it would be good for him.)

**IMPACT ON THE RESEARCHER**

Several nurse researchers have discussed the role conflict experienced in putting their professional persona aside in order to undertake a research role (Cowles 1988; Fowler 1988). An approach was thus taken to minimise the conflict between the roles of nurse or concerned person versus researcher (see Krishnasamy and Plant 1998). Realising that the beneficial elements of the research itself, and my interactions with the participants, would not ‘contaminate’ the data but in fact were data, was helpful. Nonetheless, spending many hours listening to some extremely difficult stories was very draining. As a nurse or even a counsellor there would always be limits on the amount of time spent with one individual. For a counsellor there would be professional debriefing, for a nurse on the ward there would be the social exchange and support of colleagues. There would also be the satisfaction of knowing that one was actively doing something in an attempt to ease that person’s situation. In this research there was no debriefing, no social exchange, merely the frustrating trip home on public transport. Cannon’s paper about the stresses of her research interviewing women with breast cancer was helpful in defining some of my feelings about this (Cannon 1988).

In fact gaining access to participants was in many ways the most stressful aspect of the research. The times that most I dreaded were the initial phone call to the patient, knocking on the door at the first visit and asking for consent to approach a relative at the end of the first patient interview. I presume that this is also because these are the steps into the unknown, the ‘blind date’ aspect of the research (Ball 1990).
On the other hand, another area of difficulty for me was my disengagement from the field. This must be for a number of reasons. One is a feeling that I am abandoning the participants, particularly as so many have said how helpful my visits have been. I had feelings of guilt that once the research data was in the bag it seemed I no longer wanted to know. I also anticipated that for some of the participants things may have got a lot more difficult and found it hard to accept that I may never know. Indeed, I kept in touch with a few participants for quite some time.

I became very fond of many of the people I met during this research. I still think about them and my memories are very detailed. The analysis of the interview data meant I constantly relived my encounters with the participants. Young and Lee (1996) have looked at fieldworker feelings as data in relation to the analysis, examining the 'complex relationship between emotions felt and emotions acknowledged' (p.98) believing that the roots of emotional difficulties during fieldwork need to be explored. They suggest, following the work of Hochschild the need to reflect on 'emotion work' which Hochschild defines as 'the act of trying to change in degree or quality an emotion or feeling' (Hochschild 1979) p.561, and on 'feeling rules', the social guidelines which direct how we try to feel. They remark that there may be many reasons why fieldworkers may not be reliable informants on their own feelings and actions and recommend structured debriefing interviews to explore this which then may be used in the secondary analysis (Young and Lee 1996).

Rowling (1999) describes the keeping of a research journal as distinct from field notes to record her own emotional reactions to her work. This journal she believed documented her reflexivity but also formed a supportive role as a form of ‘debriefing’ (Rowling 1999). My own debriefing unfortunately remained largely with my more general field notes and my need to ‘go on’ about the interviews was difficult to facilitate at college. Laslett and Rapoport recommend close supervision for researchers involved in longitudinal interviewing with families (Laslett and Rapoport 1975). I wrote during the interview process that:
'Ideally, on reflection, debriefing and discussion after each interview or set of interviews would not only have been supportive but also would have been extremely helpful in the early analysis and direction of the study.
(Upgrading report, 1992)

Like Young (Young and Lee, 1996) I had to use my own judgement about the emotional safety of a situation. Often rereading interview transcripts I would wonder why I had changed the subject or not asked more deeply about something that would clearly have been useful for the analysis. Sometimes obviously these were mistakes, but often it was because I must have sensed at the time that this might be too disturbing for the participant. I might thus be left feeling that this was not a 'good' interview but unable to unravel the reasons as to why. The lapse of time between recording the interviews and finishing writing the analysis makes these issues easier to contemplate but a fuller chance to explore them at the time would have added a clarity to my thinking and shone light on some of the blank spots in my reasoning.

A group of researchers in similar situations did finally set up a support group at college which was helpful in terms of acknowledgement and support for general issues such as personal safety and emotional overload, but provided minimal contribution to the analysis.

ANALYSIS

Arriving at a final approach to analysis
The preceding sections have illustrated some of the ways in which the process of data collection and analysis are closely inter-linked. Analysis of the data collected began at the same time as the research interviews took place. The interviews required intense concentration and were thus unforgettable experiences. Whatever later methods that I used to analyse and organise the data, one of my greatest resources was my memory which could make links and connections whilst I was thinking and writing.
Hammersley and Atkinson (1995) describe the earliest stages of data analysis as aiming to 'use the data to think with' (p.210) and they caution against forcing interpretation to fit in with pre existing ideas:

“This requires the exercise of some analytic nerve, tolerating uncertainty and ambiguity in one's interpretations, and resisting the temptation to rush to determinate conclusions” (Hammersley and Atkinson 1995, p.210)

On the way home from the interview I often listened again to the taped interview which I found helpful in debriefing from the interview. Once the interview was transcribed I carefully read the transcript, highlighting passages which seemed to me at the time to indicate (explicitly or implicitly) important aspects of the participants experience and perceptions. I also wrote comments in the margins. These notes either elaborated my thoughts about what the participant was saying or made comparisons with comments in other interviews or made reference to the literature. At the end of this process a list of the key issues for this individual was made in order to clarify these and explore them further at the next interview. On the way to the next interview (on public transport) I usually reread the interview again to refresh my memory.

To begin with I looked at the data in several ways to find out which would be the most effective for me. I soon found that I could not work 'cook book' style following only one set of instructions (as for example, Strauss and Corbin, 1990). 'Grounded theorising' in which theory is developed from analysis concurrent with data collection and guides subsequent data collection is not easy to sustain in practice (Hammersley and Atkinson, 1995). The field work was very demanding and also quite irregular with several interviews in one week and none in the next. As Hammersley and Atkinson (1995) point out, one can be well into the field work before discovering what the research is really about. Some of the issues which became apparent from the data were inappropriate or difficult to feed back into the subsequent interviews with the participants, for example their deep feeling of fear at the patient's diagnosis, or even some of the ways they might be protecting the patient. On reflection, it was the long
process of writing, reading, thinking and discussing with my supervisor which led to me to my overall view of these particular people's stories, by which time it was for the most part too late to go back and ask them about it.

After making comments on the texts themselves, I began by going through the early interviews making notes in a note book of 'everything that comes'. I then grouped these ideas together. So for example in August 1991, after I had looked at the early interviews, the emerging concepts which are the basic unit of analysis in grounded theory method were compared and grouped around 17 categories in rather spidery diagrams. I then began to write in further detail about several of these categories which particularly interested me. For example in the category, 'changes in lifestyle and perception' I wrote about 'ground change' which was about how everything for the relative seemed almost imperceptibly to have changed since the diagnosis. And in 'change of role and responsibilities', I wrote about the relative's role of 'protecting' and 'policing' the patient.

As the interviewing progressed I felt dissatisfied with at least three of the transcripts which seemed to be off 'the point'. The participants were not talking about what I wanted them to. However, I came to realise that the detail they were giving me was in fact crucial to their experience with the patient's illness which they were putting in the context of the rest of their lives. These were in some respects the negative or alternative cases (Strauss and Corbin 1990), which 'add variation and depth of understanding' (p.109). The first interviews with Jill, Julia and Jane lacked the kind of emotional engagement I had been anticipating and yet when I looked at Jane's own depression and busy life, Julia's ill health and the fact that Jill herself said that she coped by putting her head in the sand then these indeed were important data.

Nevertheless as the writing and the detail of the analysis grew there were some participants who were quoted more than others. Although the whole range of experience is included in the analysis some participants illustrated important points which could be made quite simply whilst others talked at greater length about the deeper complexities of
their situation. Also, depending on their relationship with the patient, some participants were more affected than others. I did not choose the participants and once recruited to the project they remained. Thus I did not use secondary selection (Morse and Johnson 1991), whereby 'good' informants were selected and retained at the end of the first interview. However some relatives experiences provided more detail than others - and some participants took part in more interviews and thus had more opportunity to say things.

I was concerned not to neglect the context of the patient interview. When the first three participants had completed data collection with three interviews, the interview transcripts from both the relatives and the patient were looked at together, in detail, to carefully address the background information that the patient interview provided. I had available here the data for triangulation - the comparison of data relating to the same phenomenon. This could provide a validity check and also give added depth to the description of the relative's experience (Hammersley and Atkinson 1995). This was a useful exercise but to look in depth at all the patient interviews would have been too time consuming. I was also unsure how this data would be used. In several ways, putting the transcripts together felt quite intrusive - the inconsistencies, the irritations, the depth of the relationships all became more fully revealed (Daly 1992). Furthermore, I did not want to be checking on 'the truth' of what people told me, the interviews were the participants' interpretation of events at a particular time in a particular set of circumstances. The patient interviews have therefore been utilised as the important backdrop against which the relatives' experiences have been elaborated. The majority of the patient interviews were used in the analysis of the main study (Bliss and Johnson 1993) and ten of them were utilised in a separate methodological study (Bailey 1996).

The bereavement interviews were also difficult to incorporate into the overall analysis. This was because this was a study about living with someone else's cancer, not death. These interviews took place because once started the interviewing process seemed incomplete without them. Nevertheless they were very different in nature to those which took place while the relative was alive. Therefore they have been considered in
detail but have not been discussed specifically in the analysis. They have been used instead as a reference point and illustration of the differences between ‘living with’ cancer and bereavement. (There is already a much more extensive literature about bereavement).

One suggestion for practically managing the analysis of qualitative data is to physically cut up the interviews and then to keep the relevant section in the appropriate file. I could not do this, it felt like violation of the people’s stories. Nevertheless, when I believed that I had identified most of the recurring themes I planned to use the computer to help sort and organise the data. Using a Macintosh and word processing software, a window was designated per theme and used to store the relevant data (a method similar to that recommended by Morse, 1991). I persevered with this for a while, but it made the data seem quite inaccessible.

The final practical method of organising the data worked well for me. I used a series of index cards labelled by category with the possibility of associated cards examining sub-themes or concepts relating to each category. On each card I wrote the reference to the relevant point in the transcript and my own thoughts, cross reference or literature (this is similar to a procedure described by Guba and Lincoln, 1985, for processing data). These seemed to manage the task well and also allowed for creativity. When writing I could lay them around me to help structure my thoughts. In all, 28 card codes were used with 17 sub themes – some of them were much more relevant to the final analysis than others. For example, ‘Caring’ was a card code, with sub themes of ‘protection’, ‘eating’, ‘cleaning’ and ‘coping with another’s coping’, ‘Social comparison’ was another card code, as was ‘Gender’.

The aim was of course to produce a final relatively stable set of categories - which I did (although I do not claim that it is definitive). These were naturally overlapping and inter-linking and were eventually organised for the purpose of display into a) three main chapters; the personal experience, the interpersonal experience and the experience of contact with the health professionals, and finally b) into three main dimensions of the
experience; existential, emotional and practical which together with the influences on these dimensions provided a summary framework to describe the whole data set.

The categories and concepts from the original index cards appear below as the sections and subheadings that structure the analysis chapters. To use the chapter 'The interpersonal experience' as an example and to refer back to the card code of 'Caring', this has now become a section entitled, 'Relatives as Carers', with subheadings of practical issues, need to care – coping by caring, feeding, cleaning, and gender and caring. During the writing of the analysis 'protection' was separated out and became a discrete section 'Protection Strategies' with subheadings which emerged through the process of thinking and writing of filtered communication, shielding, monitoring and encouragement of activities. Coping with another's coping', has become another separate section entitled, 'Living the Patient's Way' but is also a theme which can be seen running through the whole of the analysis.

Many of the interviews covered several aspects of life in great depth and not all of these are included the in current analysis in great detail. Lincoln and Guba (1985) recommend being all inclusive in the early stages of analysis - it being easier to drop, rather than recapture information at a later date. Having been a student of social history I became fascinated with the linking made by some participants between the difficult experiences during the war – I called these ‘War stories’, and the difficult experience of cancer. I particularly cherished the stories about the Blitz, nevertheless, these are only alluded to briefly in the final analysis.

I wrote the original drafts of the analysis in close mental and physical proximity to the transcripts. As I was writing I felt led by the words of the participants. I continued to find it difficult to fracture the data wishing to maintain 'the story' that the participants had related to me. To 'manage' this difficulty I felt compelled to write about one family’s story in full to try to illustrate their experience holistically, this forms the first chapter of the description of the relative's experiences. This was very helpful in allowing me to move on and become more analytical.
I have many notebooks full of my thoughts during this process. One of the key analytical experiences were my academic supervisions where I was facilitated to discuss my ideas in the most creative and free ranging way helping me formulate my ideas. I also found the writing of memos very useful in clarifying the dimensions and crystallising the ideas arising from thinking about the interview transcripts. Lincoln and Guba (1985) write that the primary aim of memo writing is to uncover the properties of the category, but they add that the writing of memos has both cognitive and cathartic uses (Lincoln and Guba 1985). Miles and Huberman (1994) elaborate how the writing of memos ‘tie together pieces of data in a recognisable cluster’ and they continue, ‘They are one of the most useful and sense making tools at hand.’ (Miles and Huberman 1994, p.72). Writing and rewriting drafts also enabled me to think about the data at a more abstract level.

I gave several presentations about my work during the process of the thesis, each focusing on one area of the analysis rather than the whole which I found a helpful exercise in moving forward my thinking. The comments by clinicians when discussing the issues raised by this research during teaching sessions were also invaluable.

**Is it plausible?**

This study was not set up to provide unquestionable proof about the experience of those close to someone with cancer, and it is unlikely to persuade a true sceptic to this research approach that the findings are worth attending to (Lincoln and Guba 1985, p.329). However, in order to provide ‘believable’ evidence for the reader I have attempted throughout this chapter to provide details of the decisions that were made during the process of the research and why. Koch and Harrington (1998) claim that:

“if the research product is well sign posted, the readers will be able to travel easily through the worlds of the participants and the makers of the text (the researchers), and decide for themselves whether the text is believable or plausible (our terms for rigour).” (Koch and Harrington 1998, p.887).
Assessing the quality of a qualitative research project is not simple and is dependent on many factors, however as Koch and Harrington (1998) comment, 'borrowing' evaluation criteria from one paradigm of inquiry and applying it to another is problematic’ (p.883). Nevertheless, if scientific 'proof' is not being aspired to, what is to be put in its stead? This is obviously of great concern to qualitative researchers and there is naturally no one clear answer. ‘Rigour’ is a word used by some qualitative researchers to reassure the reader that the research has been done with probity with a clearly illustrated, systematic set of practices - although it is rejected as a term by some (Koch and Harrington 1998) or others such as Sandelowski (1993) as having the potential to make the research process too rigid in the search for validity. Sandelowski comments:

“It is as if in our quasi-militaristic zeal to neutralise bias and to defend our projects against threats to validity, we were more preoccupied with building fortifications against attack than creating the evocative, true-to-life, and meaningful portraits, stories, and landscapes of human experience that constitute the best test of rigour in qualitative work.” (Sandelowski 1993, p.1).

Sandelowski continues, ‘rigour is less about adherence to the letter of rules than it is about fidelity to the spirit of qualitative work’ (p.2).

In this chapter I have made reference to rigour, particularly to Webb’s (1984) belief that one of the most important elements of rigour is honesty, and Ball’s (1991) view that rigour is achieved by the self conscious reflection on the links between the social and technical trajectories in the process of data collection – Ball’s definition of reflexivity. Both of these approaches to rigour have been important to me but no one set of rules has been applied to the conduct of this project. The approaches taken have been chosen as being suitable to the task in hand. The underlying research philosophy has been to be appropriate and sensitive to aims of the study and to match this with my own personal capabilities and resources. The aim is to provide an understanding of the close relative’s experiences and the intention of this chapter to provide clarity about the choices made and the influences on these choices in the way this has been achieved. As in all research, whatever its claims, the reader will make their own mind up about its merit or
usefulness.

Nevertheless, great care has been taken to undertake the research in a way that will strengthen its claim to being a plausible account of these particular people’s experiences. Guba and Lincoln (1985) have addressed what appropriate criteria may be used to establish the ‘trustworthiness’ of a naturalistic inquirer. They have suggested and discussed techniques to establish ‘credibility, transferability, dependability and confirmability’ as more pertinent ways to persuade the reader that a piece of research is ‘worth paying attention to, worth taking account of’ (p.290). Whilst not all of their tenets have been applied to this research (as Guba and Lincoln point out emphatically ‘they are not prescriptions of how enquiry must be done’ (p.331)), in many instances these criteria do coincide with the design of this research and in particular the means for ensuring credibility. For example, there was a ‘prolonged engagement’ in the field – which Guba and Lincoln believe guards against ‘misinformation introduced by distortions either of the self or of the respondents, and building trust’ (p.301). In this study, interviewing took place over three years and each individual family was followed up over a considerable time period. Furthermore, I did have previous knowledge of the hospital culture of cancer care which gave me a background understanding of some of the issues, although hearing individual’s stories in their own home was a new experience. There was also ‘persistent observation’ as I went back to the same families to review the issues that I believed had emerged from their stories and to find out how things had changed with time. In grounded theory, recurrently returning to the same theme with the participants tends to eliminate the chance of the data being unreliable. The goal is to produce a representative picture of experience and ‘validity’ will be established by the readers recognising it as such (Brink 1991). As indicated earlier I do not believe that I reached a point of ‘theoretical saturation’ (Strauss and Corbin, 1990, p.189) probably because my initial field was too broad, however, collecting more data would have made the project unmanageable.

‘Triangulation’ is a further technique for improving credibility (Guba and Lincoln, 1985) and has been discussed earlier with reference to the comparison between the
interviews with the person with cancer and their relative. However, although the patient interviews were not directly used, the reflective nature of the field notes helped to make sense of the story in relation to the other relevant factors in the situation. Demographic information and details from the post interview questionnaires were included to provide further context for the interview data. Triangulation may also be achieved through what Lincoln and Guba describe as 'contextual validation'. The issues emerging from the analysis were compared with other literature looking at similar issues in this area. It was illuminating to find ideas which had surfaced from analysing this data explicated in other areas of the literature, for example, 'coping by caring' (Benner and Wrubel 1989).

As discussed earlier (see Impact on the Researcher) a better social structure for examining and discussing the interviews might have been helpful. 'Peer debriefing', is suggested by Guba and Lincoln as 'a process of exposing oneself to a disinterested peer in a manner paralleling an analytic session and for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind.' (p.308). A few interview transcripts were read and coded by three experienced researchers to look at the quality of the interview and issues emerging from the data. Their coding was broadly similar to my own, although inevitably stamped by their own concerns and interests.

The interviews themselves were all unique experiences. Edwards (1993) argues that rather than ensuring what goes into each interview is the same in order to establish 'reliability' and 'validity', researchers conducting in-depth interviews should work towards making sure that what comes out of each interview is of the same quality – that there should be the same degree of understanding of what is happening in each participant's situation (Edwards 1993). However, with such a varied research population a similar understanding could not be reached with each individual. Nevertheless, by putting the interview in context and being transparent about the interaction it is hoped that what was produced was relevant for each individual.

Sandelowski (1993) writes that if validation is viewed culturally and historically both
experimental and interpretative researchers may be seen as relying on contextually
grounded practices rather than on rules sufficiently abstract and universal to be applied
to every project;

"Trustworthiness becomes a matter of persuasion whereby the scientist is
viewed as having made those practices visible and therefore, auditable; it is
less a matter of claiming to be right about a phenomenon than of having
practised good science." (Sandelowski 1993, p.2)

Guba and Lincoln describe the process of an 'audit trail' and although I would feel
embarrassed if someone were to look into my index cards, comments on papers read,
rather messy research diaries – they are all there along with the tapes, questionnaires and
momentos from the interviews! I have found referring back to these sources constantly
useful whilst writing, they do illustrate the process I have been through. This does not
necessarily make these findings more plausible but the existence of this trail would be
helpful in making a judgement upon their plausibility.

METHODOLOGICAL CONCLUSIONS

How, then, would I summarise my methodological approach? What is my stance on
analysis and data collection. My main preoccupation was to elicit the stories of the
research participants and to present them in a way which made them available to the
reader and, in that respect, this work has points of contact with narrative analysis:

A concern with maintaining the integrity of the data and the authentic voice of the
participants.

Susicion of fracturing the data for the researchers' own purposes, or submerging the
data in 'external' theoretical perspectives.

It is for this reason that I ultimately part company with the style of data analysis
associated with grounded theory, but I also did want to learn some of the lessons of that
tradition. In particular it seems to me that close levels of data coding and 'constant comparison' can facilitate a sensitive reading of the data sets and allow some of the themes (as well as discrepant cases) to be drawn out. In particular I have tried to complement the presentation of the stories with:

*The organisation of the participants accounts within a broad and analytical framework derived from close reading of the data.*

*An explicit account of the basis of the analytical framework and its grounding in the data.*

Thus far my approach could be summarised as an attempt to find a balance between grounded theory and narrative approaches to analysis but this is perhaps too neat and benefits from hindsight. What I wish to stress here - as the driving force of the methodology - is the continuity between the data analysis and collection processes and the importance I attached to making sense of the data as part of my ongoing relationships with the participants. I was making sense of, and trying to maintain the integrity of, my relationships and not just my 'data'. The balance of the analysis emerged through this broader set of processes. The best way of summarising this is perhaps through the ethnographic category of reflexivity. I am interested in:

*Collecting and analysing data in a way which enables me to preserve my integrity and priorities as a person, and as a cancer nurse, and which respects the needs, sensitivities and preferences of the participants.*

*Trying to represent, as honestly and as far as I can, how my experiences, perspectives and choices have shaped the analysis and data presented.*

There are also some lessons which may be drawn from my experience of this research, which I will express as 'practical imperatives' for anyone embarking on similar research in the future:
The researcher's priority should at all times be the research participants' well-being, and all methodological decisions should support this, rather than the research interactions being led by some more abstract methodological premises.

When researching a potentially distressing topic it is vital not to undermine the participants sometimes fragile 'coping' mechanisms. The interview should be determined by the participant's level of understanding and way of living with the situation. Furthermore, a contact number should be provided for the research participants after the interview and if there seems to be a need to intervene in the situation then this should be carefully negotiated with the participant at the time of the interview.

The relevance and value of institutional ethical approval should always be considered before approaching people to take part in a study concerning health related issues.

Some form of debriefing framework should be instituted for the researcher, for both psychosocial and analytic purposes. This requires commitment from others in terms of both time and financial resource.

**SUMMARY**

The process of this research has been elaborated in some detail in order to be transparent about how the chosen research methods interacted with both the data collection and analysis. The influences on these methods (both academic and personal) have been illustrated as have how decisions were made and changed with the ongoing project.

My interactions with the participants began to reveal much about their experiences even before the transcripts were examined. Therefore details about the participants have been included at this early stage to facilitate the discussion of this phenomenon. A great concern during this project was its potential impact on those taking part. This was
carefully monitored with no indication that any had any regret about participating — although some wanted only a shortened involvement. Furthermore many commented on how helpful had been the (in many cases unique) opportunity to talk about their experiences to someone not closely involved. The analysis of these data is not aiming to provide the ‘truth’, rather a plausible account illuminated by other literature in the field, and set in the context of the confines of this study.
PREAMBLE TO THE ANALYSIS CHAPTERS: AN OVERVIEW OF THE RELATIVES' EXPERIENCES
INTRODUCTION

In the next four chapters, analyses of the accumulated data have been structured together, each from a different perspective. There is overlap between the chapters which should be regarded as complementary and inter-linking rather than mutually exclusive. Whilst trying to maintain an awareness of the individual and varied experiences the chapters are structured to address common aspects of the experiences. Throughout these chapters I have striven to maintain the balance between the varied, individual, experiences and their common features, and avoid over simplification of the diversity expressed by this small and disparate group of participants.

Chapter 4: A single family experience
This presents the interviews from a single family, including those with the person with cancer. It is an example of the first stage of analysis and as such may be seen as (in some respects) relatively underdeveloped. This chapter stands in a rather complex relationship with the rest of the thesis. For example, although this particular family are not being presented as representative, their experiences do start to suggest analytical rather than just descriptive categories, some of which were subsequently developed and deployed in the analysis of the whole data set.

Chapter 5: The personal experience
This chapter focuses on the personal experience and feelings of the relatives of people with cancer. It deals primarily with the existential and emotional changes they experience and how this might affect the relative’s functioning and alter their outlook on life. This also includes some of the ways that the relatives may adapt to living with their changed circumstances.

Chapter 6: The interpersonal experience
This chapter addresses the interpersonal and social experience, the changes in the relatives’ lifestyle and interactions with the person with cancer. The chapter considers
the relative’s desire to protect the patient and the impact this may have on communication as well as the caring activities which this might involve.

Chapter 7: The experience with the professionals

This chapter reviews the nature of the interactions of the relatives in this study with the health professionals and considers why they were so minimal.

The influence of other factors on the experience, such as the relationship with the person with cancer, the type of cancer, gender, other life circumstances and the effects of time are woven into these chapters. The bereavement interviews recorded were very different in nature to those which took place whilst the patient was alive. They were not included in the main analysis of the study but have been used where appropriate to inform the findings presented here, particularly to contrast bereavement with the experience prior to the death of the patient.
Chapter 4

THE EXPERIENCE OF A SINGLE FAMILY
INTRODUCTION

The data upon which this thesis is based is arranged in red cardboard files. Each file contains all the information about an individual family, including: interviews, transcripts, letters, questionnaires, hand written notes on preliminary analysis and relevant journal or even magazine articles. Thus rather than chronological or thematic divisions in the data it was initially stored and thought of in terms of family relationships. This storage classification has remained, providing an efficient system for retrieval and probably closely mirroring how the data is ‘stored’ in my head.

This chapter is an introduction to the data. The interviews recorded in this study each contain a unique experience of living with a relative with cancer. They represent the participant’s own analysis of what has happened to them. Graham (1984) writes that “in stories data and interpretation are fused”. Breakdown of the text risks losing something of the context of participants’ intricate accounts and threatens misrepresentation of their meaning. Nevertheless, binding together all the participants stories in the hope it would pass as a Ph.D. thesis is not an option!

Before being able to create a coherent structure to represent elements of all the participants’ experience of cancer, I believed that the analysis had to contain at least some attempt to represent a family’s story ‘in the round’, without very much outside interpretation. Writing in detail about one particular family’s story thus became a necessary stage in the process of the analysis. This then enabled me to move on to think more clearly and deeply about the data set as a whole. On reflection, towards the end of the study and further removed from the data collection perhaps it does not appear to be quite so vital. However, it is still useful as an indication of what the relatively ‘raw’ data looked like.
Faraday and Plummer (1979), in making their case for the value of life histories as a research method describe some of the reasons why it is helpful to write in depth about the experience of one particular family:

“Most social science in its quest for generalizability imposes order and rationality upon experiences and worlds that are more ambiguous, more problematic and more chaotic in reality. If we check our own experiences we know that our lives are flooded with moments of indecision, turning points, confusions, contradictions and ironies. Most social science glosses over this interstitial but central region of our lives.” (Faraday and Plummer 1979, p.776).

This chapter consists of some elements of what Admi (1995) describes as a life history approach “holistic, subjective, contextual, and dynamic ....... based on a collaborative process” (Admi 1995, p. 186). Nevertheless, this research and even the concentration on one particular family does not constitute a complete life history. The interviews were all focused around one issue; the diagnosis of cancer. And whilst this event was always placed in context it did not encompass the entire experience of the participant’s life. Furthermore the maximum number of interviews with any one family member was three.

Corbin and Strauss (1988) discuss the tension between the presentation of the theoretical analysis and the use of the participants’ own words to illustrate this. They acknowledge that the relationship between analysis and data is difficult to balance. There is a continuum of the degree of analytic input by researchers into their data with at one end long quotation of raw data and minimal analytic input and at the other theoretical presentation with little close relation to the ‘natives’ experiences. Corbin and Strauss (1988) resolved this issue by developing their theoretical formulations in the early chapters of their book about managing chronic illness at home and illustrating this further with case histories in the latter ones.

Here a minimally developed example of one family’s experience is used to illustrate both the data and part of the process of the early analysis. The subsequent chapters will
bring together and compare issues arising from all the interviews and illustrate the patterns of the whole data set.

A further function in writing an overview of one family's experience is that it provides the opportunity to describe the chronology of the illness. One aim of this research has been to see how the families' experience of cancer develops over time. This concern is reflected in the analysis, but the illness trajectory has not been used to organise the overall structure of the thesis. This focus on one family is a useful way to illustrate how they might move through the phases of the illness.

THE CORNWALL FAMILY

In the red file belonging to the Cornwall family there are eight interviews, 5 letters and 2 postcards, 4 Christmas cards, a funeral order of service, completed questionnaires and a journal article.

This family were chosen because they represent quite a complete data set with two interviews with the patient participant, three with the partner (one bereavement) two with one daughter (one bereavement) and one with a son. In the majority of interviews with this family they were able to give a very deep personal insight into their experience. Also for several reasons, they were a family with whom I felt myself involved: their open, warm and whole hearted support of the research and of me, their very difficult experiences with the cancer and the fact that (although I did not necessarily get on with them better than other participants in the research) I felt that we had a good relationship.

This family also exemplify many of the ethical dilemmas that I experienced during this study and in writing about them the problem of confidentiality discussed in the previous chapter becomes particularly acute. By changing some details I have attempted to ensure that their anonymity will be preserved to the outside world and, in the unlikely event of self recognition, I hope that the content would not cause undue distress.
Despite the desire to present this family's story in a relatively unedited form some interpretation of the stories has taken place. For example, the selection of the quotations which have been fitted to the researcher's pattern rather than the participants'. This family's story will commence with a description of each family member including the person with cancer. I will also provide reflections on my own experience of researching this family. The history of the illness from pre-diagnosis to bereavement will then be elaborated and finally, some of the issues which arise from the interviews will briefly be discussed.

The family discussed here is a traditional 'nuclear' family; married couple and three grown up unmarried children, one of whom was not interviewed because she was working some distance away. There were no close outside links, only one grandparent survived whom they saw infrequently. There were many friends but family boundaries remained high and intimate knowledge was not shared. This family became involved with the research project following the diagnosis of an unusual type of cancer in Karen's bladder.

The family live in an interesting old house rendered less comfortable by Stephen's (husband and father) conscientious attempts to restore it. The interviews for this research describe the impact of Karen's diagnosis, treatment and the death over a 15 month period.

**Karen**

Karen was in her late forties, she had three children and worked part time. Karen's children were central to her life. In contrast to her husband she was meticulously organised, and a great letter writer. I interviewed her twice, and she died unexpectedly just before I was to interview her for a third time.

The first interview with Karen is one of the longest in the study (35 pages). It tells of her long, painful, humiliating road to diagnosis. The second interview tells of her depression and struggles to come to terms with her stoma where her natural coping
strategies seem to have been battered by the small amount of professional support she received.

Karen had symptoms for nearly a year before she was diagnosed. She describes episodes where:

"I was screaming because the pain was so intense"
[Karen 1 p.2]

But she had great difficulty getting her symptoms acknowledged and did not feel listened to by the professionals:

"she [the doctor at the hospital] implied that I was making a lot of fuss about nothing and if I'd been told to take the pills then I should jolly well take the pills and that I hadn't got any pain".
[Karen 1 p.8]

There were long delays in the process of Karen's diagnosis; investigations were cancelled, letters got lost or were not sent. Eventually on Karen's second admission to hospital for tests, about 10 months after her initial problems Karen was told that she had a lot of internal scarring in her bladder. The hospital consultant explained that this could be sorted out with "no problem", and provided Karen with a booklet to read about how this would be achieved. This was how Karen found out she was to have a stoma. She described her reaction as thinking, "it was the end of the world" [Karen 1 p.12].

Two weeks later at an outpatient appointment Karen was told that she had cancer. Karen explained that she knew that something was serious when the consultant asked if anyone was accompanying her. In fact Karen's reaction to hearing the diagnosis was to put her "on a high". She moved into a phase of manic activity. She describes how she approached her next appointment a few days later:

"I had put on my best suit and I had done my hair the night before so that I was really looking .....well I felt I was looking a million dollars and I thought
if I go dressed like this...there can’t be anything wrong with me .....you know, it’s all a mistake and that’s what they’ll tell me”

[Karen 1 p.17]

Despite this, Karen was admitted for surgery. After the operation, Karen said she was totally confused by the instructions she had been given about managing her stoma and felt - and was told by the stoma nurse - that she should be coping better:

“and that’s the thing that annoys me... that I haven’t been in control of my emotions and you feel such a baby and at my age sitting there and crying”.

[Karen 2 p.4]

Karen was aware her husband knew how she was feeling but felt she couldn’t keep telling him how bad it was. She did not really acknowledge that she had cancer to herself until some time after she got home from the operation. She then became quite anxious, however, she still did not feel she fully understood her illness:

“I think really I haven’t understood enough about everything and I don’t know whether it’s ...has been explained to me and I haven’t been able to take it in or ...or whether it hasn’t ....just hasn’t been explained to me”

[Karen 2 p.18]

Karen elected to go into hospital to have further major surgery to give her a different type of stoma that would be easier to manage. She had made her mind up to get rid of the “swishing and wrinkling bags” that had so tormented her. She died from the complications of this surgery.

Stephen

Stephen was in his early fifties and had a successful career which enabled him to keep the family comfortably. There were three long interviews with Stephen (22, 24 and 30 pages). These took place four and seven months after his wife’s diagnosis with cancer and at three months after her death. All the interviews with Stephen were quite emotionally charged and he was often on the verge of tears. During the bereavement
interview his distress was almost overwhelming and I tried to discourage him from making a recording, but he was insistent that we did so.

Stephen believed that his relationship with his wife was unusually close:

"I think that we probably are exceptional in being much more interdependent than a lot of people”.
[Stephen 1 p.23]

His life was completely overturned by Karen’s diagnosis of cancer (of which he had few premonitions). During the interviews Stephen talked about his wife’s illness in terms of ‘we’ and ‘ours’ indeed he told me:

"I have on occasion I suppose felt her symptoms”.
[Stephen 1 p.9]

The threat of Karen’s illness prompted him to immediately take unpaid leave from work. He felt it was at least as much his own needs as his wife’s which led him to change his life, he commented:

"I don’t miss [work]. Um which is strange because I am I think I certainly had been quite ambitious um but um no it’s something that doesn’t worry me at all. I suppose it’s just a different outlook”
[Stephen 1p.17]

Stephen and Karen had an agreement to talk openly about the illness. However, Stephen did not tell her that he had been informed by the doctor that the cancer cells that she had were of the “worst type”. Instead, Stephen commented he preferred to keep a “quiet eye” on her. Furthermore he also attempted to protect Karen from some of the rawness of his own grief, particularly after she was diagnosed:

"after she had gone out and I was on my own doing something I would quite often break down and cry um but she didn’t realise that, at least I don’t think she did”
[Stephen 1 p.9]
Stephen talks at length about the “anger and frustration”, that he felt the delays and poor communication during his wife’s lengthy diagnosis and treatment. However, he comments:

“you don’t want to upset the person who is in charge of your treatment, so you don’t feel that you can do anything about it”.
[Stephen 1 p.3]

On another occasion he describes his involvement with the hospital system as being, “lost in a great machine”, but he does not himself seek any additional information to help find his way.

Stephen’s account of his farewell to his wife as she was rushed back to theatre for emergency surgery was very moving. He and his wife had both been told that the situation was serious and Stephen was told separately “to prepare yourself for the worst”.

After Karen died, Stephen describes himself as feeling “numb” and “detached”, keeping a “stiff upper lip” at the funeral. He describes his grief as cyclical, going from not feeling “anything at all”, to suddenly seeing “no future and no purpose in doing anything”. At four months he describes it as:

“a physical emptiness. I wouldn’t have believed how physical it was and how non mental it was...it’s .....a straining sometimes, just to get some sort of contact, and touch people”.
[Stephen 3 p.13]

Louise
Two interviews were conducted with Louise, one was about nine months after her mother’s diagnosis and the other about four months after her death. They both took place at her rented flat and on both occasions she cooked me a vegetarian supper.
I found these interviews challenging because Louise was closer to me in age and social class than any other participant in the study. Oakley comments that the ethical dilemmas are greatest where there is least social distance between the interviewer and the interviewee (Oakley 1981). This is confirmed by Finch when she interviewed clergy wives of whom she was one, the participants identified closely with her, she easily obtained much confidential data which left the participants vulnerable if it was misused (Finch 1984). For me, our similarities made me nervous, both in terms of my performance as an interviewer and my justification for the research methods that I was using. I also found myself identifying with her more than most other participants. She herself was surprisingly “honest” about her private thoughts and feelings about her mother’s illness - she did not seem to be constructing a picture of how she thought I would think she should be behaving.

Louise was at an age where she was beginning her career and trying to work out what she wanted from life. She enjoyed the background stability and support from her parents but wanted her independence. After she heard her mother’s diagnosis she says:

“all I could think of was...what’s going to happen to me, who’s going to look after me...she was going to organise my wedding and look after me when I have children”.

[Louise I p.2]

Nevertheless, Louise also found one of her mother’s rationalisations of her disability difficult:

“she said ...okay she could cope with one of those bags, as long as she could have grandchildren...and I just felt...oh don’t put that pressure on me, you know”.

[Louise I p.15]

Louise felt responsible for her parents, but also that their needs could potentially be quite burdensome. The strain of her mother’s illness surfaced at times with arguments with friends and tearful episodes at work. Nonetheless she said that she was able to forget
about what was happening and seemed to seek distraction, for example a new boyfriend
the night of Karen’s first operation. She described one of the ways she coped:

“you just block your mind, you don’t think that it’s anything serious”
[Louise 2 p.6]

When her mother finally became very ill and Louise remarks:

“even an idiot like me could understand that it was pretty serious now”
[ Louise 2 p.7]

However she still then went away for a short holiday with friends - only to have to return
immediately the day before her mother died. Louise said that her sister later told her that
Louise did not want to know what was happening. Louise describes her bereavement
over the first few months as not really “thinking that much”. However, more recently
she had been allowing herself to “wallow in it”, particularly by being “miserable” in the
bath.

Robert

The single interview with Robert was quite difficult. I had not initially planned to
interview Robert, but his parents, both of whom were very protective of their son, asked
me to record the interview because they thought it would help him to have the
opportunity to talk.

At the time of interview (nine months post diagnosis) Robert was aged 18 and having
left boarding school he was working in a shop before travelling in a year off before
university. Both he and his father admitted to a strained relationship with each other
punctuated by explosive rows. Louise described them as both “vying for mummy’s
attention”, Robert admitted that he was closest to his mother, and both father and son see
Karen as the mediator. Robert knew little of the difficulties leading up to his mother’s
diagnosis as he was away at school and believed that things were being taken care of by
‘specialists’.
The interview with Robert was difficult to analyse. I was very aware of being a woman in my thirties interviewing a rather self conscious teenager who was desperate to leave home. His professed nonchalance is difficult to believe, yet is consistent throughout the interview. His reaction to being told Karen’s diagnosis (during a row with his parents) was to feel:

“very put out that I hadn’t been told before”.
[Robert 1 p.2]

He found it hard that he was prevented from visiting his mother in hospital when he was at home, but after he went back to school he comments:

“To be quite honest...whether it’s because I’m completely heartless or something else.. but I just..it didn’t bother me really. When I went back to school it was.. something that was happening up in London.”
[Robert 1 p.3]

Perhaps this is because of his attitude to cancer:

“I wouldn’t immediately think cancer.. ah, someone is going to die, I would just think cancer, ah it just means .. a large amount of hassle and there’s a chance that someone could die.”
[Robert 1 p.6]

Or perhaps because as he says:

“I tend to brush everything off to one side and sort of let it sort itself out, because when it comes down to it, there’s no point in sort of panicking”
[Robert 1 p.6]

Robert’s well-being and the smooth running of his life was of enormous importance to his mother and father. Karen planned his school packing from her hospital bed. His parents insured that people at school knew what was happening and would “keep an eye
on him". When his mother died, Robert was abroad, encouraged to continue his year off despite his mother having further major surgery.

**The researcher**

Unfortunately it is not possible to use a pseudonym to disguise the identity of the interviewer! I did feel very involved with this family who swiftly informed me after Karen's death. I attended her funeral where I felt enormously sad. I cried so much the woman sitting next to me became concerned and it was hard to explain that I was "only" a researcher.

Stephen commented at the end of his third interview about my involvement with this family:

"I'm sure that the fact that Karen has died must have been.. it's almost throwing you into your own research.. hasn't it.. I mean you've got .. some feelings of your own now, which are mixed up in your objective .. this is a couple and this is what's happening ... to them, and suddenly at one stage, hang on, one of the couple isn't there, hang on, what's happening to me.."  
[Stephen 3 p.25]

I wrote long field notes after this particular interview. It might be useful to illustrate with two extracts which really address many of the dilemmas I faced with this (and other) families. This particular interview followed having dinner with the whole family (Stephen was now living on his own and he felt uncomfortable about me visiting by myself so he made it into a family occasion).

I was concerned about upsetting Stephen by asking to recount his experiences at the time of his wife's death. I comment:

"And I don’t think that doing the interview did upset his balance too much. I mean I don’t think he’s in a safe place anyway, so I don’t think I could really knock him out of .....  
........and actually just doing it might have helped a bit.. although of course I felt very vulnerable, and I didn’t leave the house till.. after 11.30 at night and I’d had a wisdom tooth out in the morning, so I was feeling pretty jaded.."
when I left. Well I wasn’t actually. I feel jaded today, it’s the next day I’m doing this.”

and further on

“I got home very late after this interview and I couldn’t sleep at all and I’ve spent all day today thinking about it. And because it’s Good Friday and Jeremy’s at work... I haven’t had anyone to off load it on to. I think I put myself in a very difficult position, but I knew I was going to.. in doing this interview. I think in no other way would you sit and listen to somebody the way I did. I had to really for a couple of hours... because if you are a counsellor you have a finite amount of time and if you’re a professional you’re offering advice and if you’re a friend then you do say more, you don’t just listen, you don’t just absorb it, and... this man’s grief is so enormous... its had quite a big effect on me and I’ve actually had to listen to the whole tape again, just to sort of try and think about it and to think about whether the interview was worthwhile even and... I think it was, and I think it was for me as well, because I have been... I think I actually did need to finish off the trilogy of interviews with Stephen”

Fortunately finishing with

“I think I feel better now. I’ll go out and have a nice day.”
[Field notes Stephen 3 pp.26-30]

Stephen’s feelings about the interview process have been quoted in chapter three, however to further illustrate his commitment to this research in the context of his own grief:

“Yes, I think there’s two reasons that I wanted to give you this... chat this time. One is that I honestly believe it is very important... a very important subject that you’re doing, and therefore you need the input. But the other thing is purely selfish and that is it does help me an awful lot.”
[Stephen 3 p 24]

Louise also talked about the interviews:

“recently I talked to this girl who’ split up with her boyfriend, and how they’d been to Relate, and I just looked at her and said .. “gosh, I never could, I just could not. But then you see like .. you come to talk to us, and I
really find that useful, but I'd never have gone out to seek somebody, never, I wouldn't.”
[Louise 2 p.30]

Key Events

Getting diagnosed
No one in this family seemed to suspect that Karen had cancer before she was actually told. Stephen says that Karen “wondered” about it early on, however they were specifically informed after one investigation that this was not the case. Karen’s symptoms were those of common female complaints and she herself believed that there would be a relatively simple solution to the problem if only somebody would help her find it. Her story describes frustration and anger at the health care system but, it is not coloured by the fear of a serious illness. The delay does however take a huge toll on both her and Stephen and as with many people with cancer whose diagnosis is protracted this is reflected in the ways that they think about the illness after it had been diagnosed. As at the first interview Stephen says:

“if only they’d found things earlier, if only all the things had been done promptly ..........in our view it would almost certainly have been a lot less of a problem, ....we don’t know whether she would have needed this or not [the stoma] - but at least she would have been spared six months of continuing pain”
[Stephen 1 p.7]

Neither of the children whom I interviewed were particularly aware or involved with the process of getting diagnosed. Indeed even Stephen’s account seems relatively hazy. Thus, in this family, in contrast to many of the others interviewed for the study, it was not the partner or adult children arranging and sorting out visits to the doctor but the patient herself who was trying to get help.

The impact of hearing the diagnosis of cancer affected all four participants quite differently.
Stephen was with his wife at the consultation where she was told, "we’ve found there’s a tumour". Stephen asked immediately, "is it malignant?" Stephen’s reaction to the diagnosis of a malignant tumour was that he instantly faced thoughts of his wife’s suffering and eventual death:

"But I, I just felt there was no way that um I could go on without her and also I couldn’t, what I was looking at was er a progression of her illness getting worse and worse, having treatments which were going to be painful and were going to knock her out and all one way. And you know it was um very, very traumatic".  
[Stephen 1 p.10]

Stephen’s whole world changed from this moment, his career no longer mattered and he believed that if his wife were to die, home and his own comfort would not matter either. There was a fourteen day wait between hearing the diagnosis and going to surgery. During this time he was very tearful but also felt an acute agony of uncertainty. In both the first and second interviews he describes this time (which happened to coincide with Christmas) of not knowing what was going to happen as the most difficult. He recalls having a mental picture of:

"a cancer growing and continuing to grow minute by minute, hour by hour, day by day"
[Stephen 2 p.1]

Karen herself on the other hand seems to have reacted to the news differently, the full awareness that she had cancer did not sink in until some months later. She recalls disbelief, she says that she didn’t immediately think she was going to die and when her husband tells her he has taken leave from work she replies:

"I’m not going to die you know, I’m positive about this, it’s not that bad you know. They’ve probably made a mistake because they often make mistakes in hospital"
[Karen 1 p.16]
Karen recalled how she responded when her elder daughter asked her about her visit to the hospital. It seemed Karen did not want to allow her family any questioning or discussion:

"oh well, it was alright I’ve just got a malignant tumour but I’ll tell you more about it on Friday"
[Karen 1 p.14]

As she told me her story, it appeared that Karen was trying hard not to think about the possible implications of her illness at that time. She describes her next visit with the consultant:

"well it was wonderful you see, because well I did say to her, well it’s not terminal, she didn’t actually answer that question but I had made up my mind that I had..... that it was alright really. So we had a very jolly Christmas because I was just on a real high and nobody was going to be miserable"
[Karen 1 p.18]

Only at Church with the vicar and away from those who were more closely involved did Karen allow herself to contemplate her situation and broke down in tears.

Louise like her father thought about death when she told her that her mother had been diagnosed with cancer. She had no premonitions that her mother’s condition might be serious until just before her mother told her:

"and it was just...about half an hour after I was walking over to meet her I suddenly thought...she’s got cancer. And that was honestly the first time I really thought... that she had it”
[Louise 1 p.1]

When Louise had her fears confirmed:

"tears just poured down my face"
[Louise 1 p.1]
Unlike her father and unlike many other participants in the study, she seemed to feel no great need to hide or protect her mother from her distress. Louise took comfort from talking to a friend whose mother also had cancer. She describes going home to her parents that evening:

"It was okay because we didn’t really talk about it, I think it was a bit false, in some ways... yes I think...when the conversation sort of turned that way I think it was quickly... turned back to something different instead.”

[Louise 1 p.2-3]

Louise found Christmas very difficult that year:

"that was just horrid because I felt all that time that I should be ultra helpful, and I did not want to be there... cos you know how it is ... when you get older, and you have to stay for a whole week with your parents.... .... and then you’re feeling very guilty because you know this could be her last Christmas”

[Louise 1 p.2-3]

Robert also talks about coming home for Christmas:

"I came back for Christmas and there was still absolutely nothing, everything was fine ..apart from everyone was very much on edge, especially mummy and daddy, which I didn’t realise until... for some reason we got into a row and then I was told.. yes, she was only given two weeks to live or whatever... which was ridiculous because no one had told me before hand ...and that got me very wound up just for a few days”

[Robert 1 p.1]

This recollection seems quite extraordinary both in terms of how he was told and what he was told. Both parents were unusually protective of Robert, however they all mention rows between him and his father. He may not have had a clear recollection of the details of a very emotionally charged argument. Robert seems to have seen his mother’s illness as a threat to remain on good behaviour:

"from then on it was... be very careful, don’t make any rows....don’t wind anyone up"
However, he did not find his Christmas as difficult as his sister:

“it wasn’t the main talking point at Christmas at all ...which was, I think, probably a good thing. And then, from then on I sort of found out exactly what was happening ....sort of by and by”

Robert was frustrated by the way he was shielded from information about his mother’s illness and gradually gleans details from his mother and his sisters. However, he did not at any point express any feelings of distress to me about his mother’s diagnosis.

Like many other families in the study the ways of living with the illness were to a large extent dictated by the person with cancer. Karen’s feelings of disbelief and desire to keep up a front and have a good Christmas created the pattern that all the rest of the family went along with. This was despite Stephen’s acute feelings of uncertainty and need to ventilate his emotions, Robert’s need for more information and Louise feeling uncomfortable and “false”. Nevertheless it was Karen who kept them all going and provided each one of them with the most support at this time.

**The operation**

The family again have quite different recollections of the operation which removed Karen’s bladder.

Stephen was at the hospital for much of the time and despite his own squeamishness seeing his wife in intensive care with her many tubes he comments that it:

“didn’t actually upset me anything like as much as I would have expected”

He was concerned about how it affected his daughter. Louise believed that her father managed her mother’s hospitalisation much better than she did. She was often very
apprehensive about her hospital visits. However Louise was able to go home and go out in the evening and forget about it, at least temporarily. Whereas Stephen describes the small amount of time when he was not visiting:

"I suppose I was just keeping going I suppose. I didn’t really feel anything more than that. I really was thinking all the time about what she would be doing, my wife “is she going to be better this time when I go? I hope she’s going to be better”

[Stephen 1 p.20]

Initially Karen recovered very well, then for 10 days her condition steadily deteriorated.

Stephen describes her:

“until she really was looking like the image I have of somebody dying of cancer. In other words terribly, terribly drawn just down to a skeleton. Um and you know I couldn’t believe that, I didn’t think that she was going to die er at that stage but I couldn’t understand, surely they were going to do something and they’d get it right”

[Stephen 2 p.4]

Louise recalls:

“the worst, the really worst horrible moment was when ....... .....I went in and she just looked so grey.....just like the one corpse that I’ve ever seen, so that was horrid and she just looked awful”

[Stephen 1 p.7]

Eventually Karen was taken back to theatre to have an infection drained, from when she quite quickly recovered physically.

Robert was in many ways the least involved and he found his lack of involvement difficult:

“I wasn’t allowed to go in for week after week after week, cos it would distress me............
I can’t stand injections ...but it didn’t ..I’d have liked to have gone in anyhow. But when I eventually did go in, although apparently that day was
when they took out most of the tubes and there was only sort of a couple left, I still found myself sitting at the bedside thinking ... I wonder what that tube does...... ugh I shouldn’t have ... so I’m probably glad I didn’t go in but at the time it was.... I’d have liked to go in especially when daddy was going in every day ... and I was waiting around till about sort of 10, 11 o’clock for him to come back”
[Robert I p.3]

Karen’s recollection of the same visit shows how she wanted to hide things from her son which might upset him:

“I had said I didn’t want my son to see me when I had got tubes in...... any way he did come in with my husband on the Sunday afternoon with my husband but I insisted that he sat on that side of the bed and I could keep this arm down so although there was a thing up there he couldn’t see it here and then there was a bag .. the drainage bag down there and he didn’t have to see that.”
[Karen 1 p.27]

Karen herself recalled her experiences in hospital in great detail. For example, She recounted being extubated on intensive care (an event about which one would expect her to have no recollection):

“he’d got to take this thing out of my throat.... was it a ventilator... I think and um... I sort of clamped on to it because I was quite comfortable as I was and I really didn’t want to be disturbed so we had a little fight while he got that out”
[Karen 1 p.25]

Karen had several memories of hospital which distressed her. One, which she meant to write a letter of complaint about, was the way she was left to wait for long periods in considerable discomfort outside the X ray department. Another was recalling the beginning of the realisation that she now had a stoma. She reflected on how the delay in diagnosis may well have caused her to undergo more extensive surgery but she was too vulnerable to question this;

“I feel I have quite a good relationship with [the consultant] so I don’t want to say anything because I feel if I said that you know it would spoil it .......
...because I hate this bag so much.... it upsets me so much, you know that every so often I just think well if it had been different”.
[Karen 1 p.28]

The operation and infection left Karen “absolutely exhausted” at any activity and she lost an enormous amount of weight:

“I came out looking like something out of Belsen...in fact the Monday before I came out I was in the loo and I looked in the mirror and I looked behind me to see who was there because it wasn’t my face that was looking at me in the mirror”.
[Karen 1 p.32]

**Living with recovery**

Recovery is perhaps not the right word to use for the time after Karen came home from hospital although by the end of the year Karen wrote to me that she seemed to have achieved some kind of equilibrium.

Karen had physical, emotional and social problems to overcome with the stoma, but found it extraordinarily difficult to get help from professional carers. She describes her need for help when she first came out of hospital and says:

“that was when I really felt abandoned.”
[Karen 2 p.1]

She was desperate to get useful and consistent advice from someone:

“I thought well, where am I ever going to find anybody who is going to help me and tell me what is right.”
[Karen 2 p.3]

Instead she found herself struggling from person to person, unable to obtain any real help or even sympathy. Both Karen’s father and grandfather had committed suicide. Karen told me
“Really I felt suicidal and if I’d had the energy I would have walked up to the tube station and gone under the tube cause I had sat in the bath and thought about that because the pain was so.....”

[Karen 2 p.2]

I was very concerned following this interview. Karen had spoken to me in confidence but I felt a responsibility. I subsequently telephoned her and asked if I may consult colleagues who might help her. Karen agreed, but in the event did not want to take forward any of my suggestions. She was managing to find her own way through the difficulties.

Karen describes the help that she got from her husband at this time. He listened and gave her practical support and companionship. When she talks about her difficulties or attempts to use new equipment, she talks in terms of “we”. However she also says:

“you need somebody out of the situation really”

[Karen 2 p.11]

Stephen saw his role as encouraging and supporting his wife. He mentions the initial traumas but at no point ever complains about or questions caring for Karen. He seems to accept that they will now have a more restricted life style and “enjoyed” and even “relished” being able to spend more time at home with his wife:

“she will be restricted in what she will be able to do and therefore we will both be restricted in what we will be able to do jointly in terms of maybe travel”

[Stephen 2 p.14]

Louise found supporting her mother with her stoma much more difficult than her father did. She wished that she had known more about it before she first had to help her mother with it. She describes first seeing the stoma:

“she was so intent on peeling off the sticky thing over it, that she couldn’t have seen my absolute look of horror..... it was much bigger than I thought it
was, and it was sticking out, and I thought it was going to be .... much smoother with the surface... it was just horrible”.
[Louise 1 p.17]

However, after her initial difficulty she was able to help her mother with the “mechanics” of it and was pleased that she could do so. Robert was distressed when he was at home and he saw his mother suffering, however he never felt that there was anything that he could do to help. When he was away at school he does not acknowledge dwelling on her illness:

“I suppose the only thing, it messed up my revision for As...A’ levels, but even that, to be quite honest, it was there as an excuse to why I hadn’t done so much revision ...as opposed to a reason why ... but there we are ... but all the time at school it didn’t really strike me. as far as I was concerned they were doing the best they could ... there was no point in me getting worked up about it”
[Robert 1 p.4]

Perhaps this is because his parents went to enormous lengths to shield him from anxiety particularly whilst taking his A’ levels. Stephen explains,

“We were worried that he was going to be too upset and worried. He’s taken it remarkably well um and um doesn’t appear anyway, we’ve obviously tried to keep, get others to keep an eye on him to be sure that he’s not just bottling things up”
[Stephen 2 p.13]

Both Karen and Stephen spend some time in the second interview talking about their sexual relationship as the operation had made intercourse virtually impossible. Karen describes an early attempt to discuss sexual difficulties with her doctor:

“I said to him then, ‘will it have any effect on my sex life?’ To which he responded: ‘I’m surprised you’ve got the energy’.
[Karen 1 p.33]

Neither had anticipated the “physical limitation” caused by the operation. Stephen comments:
"And it's something quite honestly that is easier to put up with that to go through great embarrassments of discussing so..."
[Stephen 1 p.18]

For Karen the bag itself is a great impediment to her sexuality:

"it just puts me off anything at all"
[karen 1 p.34]

However for Stephen this is not the problem:

"Me personally it has never worried one scrap the fact that she has to have that bag. I can honestly say that and I didn't think before it was done that I would be able to come to terms with it without any trouble."
[Stephen 2 p.17]

Karen says several times that it took a while for her diagnosis to sink in. Her anxiety about having cancer suddenly escalated when she was required to have what she saw as an unscheduled scan. Both her husband and daughter also recall this as a particularly stressful time.

Karen describes waiting for the results:

"We came home and of course you've got that fortnight to wait well I mean in that fortnight I knew I was dying and that was all there was to it."
[Karen 2 p.13]

There was a two hour delay at outpatients to get the results Stephen describes this:

"so it's always like this, the waiting when your mind is feeding on itself and just building real mountains out of molehills um so that when she said "oh well, the scan is clear", my wife was in no condition to even hear what she was saying"
[Stephen 2 p. 8]

Louise also recalls her reaction to the scan;
"I think it was the first scan ... post op ... and it ... probably cos I was going for a job interview at the same time, it was all a bit too much, and that was difficult ... I was pretty horrible to one friend, unintentionally, things just slipped out"
[Louise 1 p. 11]

Both Robert and Louise express the uncertainty that the cancer has thrown over their lives on a day to day level such as wondering what mood their mother will be in and how much pain she will have on a particular day.

Towards the end of her second interview Karen commented that she now felt that she was regaining some of her sense of humour and becoming more “positive” about life and beginning to look for new projects. She said she had enjoyed the attention that she had from family and friends during her illness, but was feeling a need to be independent and on her own again. She was therefore glad that Stephen had decided to go back to work. Karen felt protective of her husband and now wanted to have her own conversation with the doctor without him there:

"Cause the things I want to say would upset him and I think he’s been worried enough".
[Karen 2 p.20]

It was very much Karen’s decision to have the second operation. Stephen only mentioned it briefly at his second interview as she had not decided at this point. At this time Stephen was unhappy about returning to work, unsure about a second operation, but reconciled to the fact that this was what his wife wanted and he had to go along with this.

Death
There are two interviews which tell the story of Karen’s death one with Stephen and the other with Louise. Robert was away at the time of Karen’s death and did not take part in a second interview.
After the second major operation which was carried out to make Karen's stoma less conspicuous, Stephen again spent long periods visiting the hospital and Louise found this more difficult. However they were less anxious because they had been reassured that there was no further sign of cancer and neither felt a great need to find out about the details of the operation. Nevertheless on reflection, Louise said that there were signs that her mother herself was thinking about her mortality. Louise recalls that in her letters before she went into hospital her mother was telling her friends that she felt very peaceful, which was not a word that Karen usually used. She was also struck by her mother's insistence that it was important she teach her daughter skills such as how to make curtains before she had her operation. Louise did not see her mother the day before the operation because like her brother she said

"there's only so much that you can do"
[Louise 2 p.5]

Several days post operatively when things started to go wrong Louise was not immediately informed. Again like her brother she remarks

"and I was very upset that I hadn't been told".
[Louise 2 p.5]

Karen was transferred back to intensive care. Louise was spoken to by one of the doctors who told her that her mother's condition was serious and that she would have to go back to theatre. However Louise still believed that her mother would get better and did not want to cause her father further distress. She remarks:

"I didn't say anything to daddy because I didn't know whether he had been told or what".
[Louise 2. p. 7]

As Louise had an interview for a course the next day and felt that her mother and father wanted to be alone together she left to go home, her mother's last words to her wishing her luck with her interview.
Stephen reported that he and Karen were spoken to together by the doctor when she was told she would have to go back to theatre again. Stephen was told on his own to "prepare yourself for the worst". He describes very movingly saying good-bye to his wife as she was taken to surgery:

"and I had to stop, and in effect say good-bye to Karen pretty well in a matter of seconds... literally on the run......the main thing I wanted to do was to go with her and be with her until she was unconscious, because I felt that was where she needed me to be.........

she said .. "don’t want to die"... and I said “no, I don’t want you to.....and that was the last thing we said to each other. We couldn’t say anything more because we were both ...I think trying not to cry”.

[Stephen 3 p. 4]

Post operatively Karen remained unconscious on intensive care. Despite being hopeful, Stephen describes how things “just steadily slipped down and down”. Louise, nevertheless went away on a pre planned weekend, only to be phoned soon after she arrived and told her that her mother was now almost certain to die.

After staying with Karen all night at the hospital, Stephen called his daughters early in the morning. They all had breakfast at the hospital where he said to them:

"I don’t know how..whether we’re entitled to ask ... ask mummy to.. go on any longer."

[Stephen 3 p.7]

When they returned to her bedside they were called to the doctors’ office and Stephen recalls they were told:

"we’ll go on as long as you like, but I’ve never seen anybody recover from this state, and I think really we ought to stop.. but I’ll leave it to you... I’ll give you half an hour to think about it, just think about it and tell me what you think.”

[Stephen 3 p.7]
The family made the decision to discontinue treatment. A later regret which Stephen and Louise both mention is about the speed of Karen’s death. Both wondered if they should have spent more time considering their decision to discontinue Karen’s treatment. They accepted the doctor’s advice almost without question but both of them were now troubled by their decision.

Louise remembers feeling that she would not be able to cope if her mother’s illness dragged on. Stephen felt that he could not ask his wife to go on struggling much longer so when they were told that, “there’s no more we can do”, Louise recalled (in tears):

“we just sort of discussed it a bit before he went back... and decided that... it was time to stop now, she just wasn’t getting any better. And you keep thinking... if we’d tried.. if they’d carried on, would it have made any difference”
[Louise 2 p.12]

Stephen recounted with some difficulty;

“I said ..I thought that was.. that that was it, that we couldn’t ask her any more. Since then I’ve wondered whether I was giving up too soon.. and that maybe we could have just kept going a little longer just to be quite sure there was no hope. But.. I suppose I was relying upon the doctor’s words.. which.. I felt at the time like saying, but I couldn’t... well yes, you may not have seen anybody else recover from this but it doesn’t mean to say that Karen won’t. But I didn’t. And .. I suppose I’m bound to wonder what would have happened if I’d just asked them to hang on a bit longer”.
[Stephen 3 p.7-8]

Both interviews describe Karen dying and watching the ECG monitor going to a straight line. Louise recalls:

“that was it..a straight line.. next minute... she’s gone.. cos I was feeling really awkward at one point.. before all of that.. when daddy and my sister were on one side of the bed and I was on the other.. and this.. I think she was a trainee, poor girl........... so she sort of felt I was sort of stuck on my own, and she sort of put her arm round me and I just felt really rigid”
[Louise 2 p.13]
The hospital felt it was important that they stayed to see Karen again without any tubes in but as Louise said “it wasn’t helpful”. Stephen describes it:

“she was no more like my Karen than the man in the moon”.  
[Stephen 3 p.8]

Before she died, Karen had decided what she wanted to wear for her funeral. In the event, her daughters realised too late that their father had unfortunately got the outfit slightly wrong and this became something of an outlet of tension for them. Knowing how meticulous their mother was, and their father’s characteristic lack of attention to detail, Louise said that they actually found the situation rather funny. They visited the chapel of rest where they each went into see Karen separately. Louise explained;

“I couldn’t see where they were all going, so I was wandering down this corridor and then I wandered back and said…”where is it, I haven’t found it?”... And so... I was giggling by this time.. it was just hysterical sort of giggling... I went into the chapel eventually and sort of stood in the corner, and sort of could just see mummy’s nose sort of peeking out of the coffin.. and I knew that she was going to be wearing this blouse with her suit, which was going to make me laugh anyway, and I knew she would look bloated so I was sort of looking at everything else in the room, and I eventually go to the coffin and sort of peered over, and I honestly can’t remember what she looked like, ‘cos I took one look and I thought, no, I don’t want to remember her like this, because it’s not her.”  
[Louise 2 p.18]

One of the practical difficulties and source of tension after Karen’s death was that Robert was difficult to contact. By chance he telephoned the night that Karen died. Robert returned home and his father and sisters went to meet him at the airport. Robert’s friend was with him and it was hard initially to talk about what had happened:

“It was all very jolly conversation on the tube, until B. left and then.. you know”.  
[Louise 2 p.16]

Robert was not interviewed after his mother’s death. When Louise was asked how he had reacted she said:
"He wrote it in his diary and he let us read that, and I think that was his way of telling us... and he said that on the Monday...(his friend)... sorted out...dreadful thing.. the flights home.. and he went and sat in one of the churches that he’d been to, and he said he just wept for an hour.”[Louise 2 p.15]

Louise mentions that in their discussions about the funeral her father cried which her brother found very difficult. At the funeral both Stephen and Louise mention maintaining a “stiff upper lip”. They both found the funeral a source of comfort and an appropriate memorial to Karen, and they were pleased with how many people attended.

EMERGING ISSUES

This chapter has concentrated on the story of one family. It has described some issues which were specific to this family. As is shown in subsequent chapters, there is also substantial overlap with themes from other participant’s accounts.

This is a story of a relatively close ‘happy family’, yet communication between the family members was strained and at times difficult in their endeavours to protect each other from as much distress as possible. The family expressed the difficulties of witnessing the physical and emotional changes wrought by the disease and its treatment - although Stephen (like many others in the study) took satisfaction from how he managed this. This history illustrates well what a relentless and pervasive illness cancer can be.

The family member’s relationship with the patient was an important factor in mediating their experience - which was very different for each of them. Stephen, exemplifies the life cycle model (Carter and McGoldrick 1989) when he explains how much harder it is to be bereaved of a partner than a parent:
"I can see all the difference in the world between losing a parent and losing a partner. I mean there is no comparison at all. And I was very fond of both my parents".

[Stephen 3 p.16]

Stephen experienced a complete change of perspective when Karen was diagnosed with cancer. Stephen could not think of anything else but to be with his wife. Stephen's adult children felt differently. Louise used the word "duty" when she thought about the support she feels she should be giving her parents. Stephen had an important job, but it was easier for him, both psychologically and practically, to take six months off than it was for his daughter to miss an interview for a place on a course when her mother was on intensive care.

Financial security was an influence on the experience of illness for this family and Stephen's ability to take time off work to be with his wife was very important to him. Gender also appeared to make a difference in terms of caring responsibilities for the children, although Stephen did not appear to be what may be perceived as 'typically' male in his attitude to care and, as he commented several times during the interviews, he surprised himself by this.

The stories told by the individual members of this family are at times inconsistent and conflicting. However, there are also some issues or reactions which are strongly similar. So for example the whole family shows a certain amount of what they call "brave face" as a way of dealing with the illness.

Bury (1988) concluded from reflection on his research about the experiences of patients with arthritis and their families that "cultural constraints rather than psychological disposition are at the heart of the problem [the anxiety about the illness]". He continues that the response to rheumatoid arthritis "though contingent or emergent in character is also socially patterned" (Bury 1988, p.113). This family's response to the illness also appears in many ways to be 'socially patterned'.
Taylor (1983), looking at the adjustment of cancer patients to threatening events, described self-enhancing comparisons which may also bolster self-esteem; anyone may be better off as long as the comparison is with someone who is perceived to have greater misfortune (Taylor 1983). Stephen and Louise both exhibited this strategy – as did several other participants:

“and you know, you start counting your blessings.. like .. people with facial stuff.. how dreadful that looks, whereas her’s was nicely hidden.. and she was.. she had a good lifestyle.. for the last year”

[Louise 2 p.27]

This family did not make great attempts to control the situation. There often appeared to be a feeling that the course of events would largely depend on fate - over which they felt they had little control. The children particularly talked about this and this seemed to make them feel quite helpless. When discussing the amount of information she received when her mother was seriously ill Louise remarked:

“I mean at the end of the day it doesn’t matter what you are told, does it? It’s not going to bring them back or make them any better.”

[Louise 2 p.27]

It is a challenge to generalisations about middle class professional families, that this family did not seek more information or be more actively critical of Karen’s care. Along with the “stiff upper lip” there seemed to be an attitude that one should not complain about things. This may in turn have been linked to an underlying fear of what was happening (along with a fear that to question the professional wisdom may result in even worse care). Wealth and education did not facilitate easier access to information or a better service.

This family's story illustrates the danger of professionals making assumptions about people. The professionals did not appear to allow due time to listen to these individuals and even fundamental information about the treatment and follow up was omitted. In
particular, the final 'quick' decision about turning off Karen's life support had long term ramifications for her family.

Finally, the members of this family, with the exception of Robert, wanted to talk about what had happened in some detail. They exhibited an 'impulse to narrate' (Sandelowski 1991). They said how helpful it was to be able to talk freely about their experience - which they had little opportunity to do elsewhere. There did not appear to be any discernible need to impress me or influence my perceptions of the data. As far as it is possible to tell these were 'private accounts' (Cornwell 1984).

SUMMARY

This chapter was first drafted at an early stage of the analysis when I believed it was important to maintain the integrity of at least one family story, including the experience of the person with cancer and to a lesser extent the researcher. This chapter also closely follows the experience of the disease trajectory, something which is alluded to but is not part of the framework of the other chapters.

The interviews with the Cornwall family, as presented here, have remained relatively undisturbed, with minimal analytic input. This family is not intended to be representative. Indeed some differences such as relative wealth, education and the number of family members involved, set them apart. However it is presented to 'set the scene'. Most of the issues raised by this account are not unique to this particular family and will be developed further through the ensuing chapters.
Chapter 5
THE PERSONAL EXPERIENCE
INTRODUCTION

The dimensions of an individual's distress may be difficult for others (or even the person themselves) to understand or gauge. From these interviews it was evident that for many there is a deep ‘existential’ element to this experience which may be difficult to identify or talk about, but in essence is a fundamental loss of bearings and sense of unreality created by the threat on the life of a loved one. This may be accompanied by a more tangible change in outlook, for example in life’s priorities or direction. Then there is the emotional disturbance which may be described as feelings of sadness, depression, anxiety or anger. It may also be felt as physical sensations; “dry mouth”, “hot feeling”, “jitters”. Finally day-to-day functioning might be changed or impaired, for example there might be weight loss or tiredness and loss of sleep. The different elements which make up this experience are not mutually exclusive and will thus interact with each other. So, for example, the most abstract and general feelings such as unexplained fears may cause the more concrete physical manifestations such as insomnia.

These experiences will naturally all change over time and will depend in part on the state of health of the person with cancer. The illness trajectory will vary considerably between families because of many factors, such as the site of the primary cancer or treatment - although some parts of the trajectory (e.g. immediately after diagnosis) share striking similarities. The experiences described here are distressing and difficult but it would be a mistake to see the personal experiences of relatives as wholly negative or passive. It is important to understand that relatives, at least those in this study, do find ways of living through these experiences and responding to them.

EXISTENTIAL DIMENSION

Threat to internal security
This section elaborates the loss of bearings and internal security experienced by many of the participants in this study. For some this was transitory and had recovered even by the time of the first interview, for others it was still very evident after three interviews.
This existential nature of the experience is difficult to identify because for many of the participants it was an unspoken change in outlook after their relative became ill. Thus this is an attempt to describe a fundamental change which is in some instances implied rather than articulated. In some cases it is only recognised by the participants themselves after it has passed and life had become more ‘normal’ again.

Despite some improvements in treatment and survival rates, cancer does appear to have a unique ability to inspire fear and dread - and the participants in this study were no exception to this. Most of the relatives intimated at some point in the interviews that the diagnosis of cancer had caused them to consider the patient’s death. This was usually most painfully acute at the time of the diagnosis.

Although in the past the participants may have thought about death in the abstract they were now faced with real threat to the life of someone they cared about. Andrea described her thoughts and feelings when her husband was diagnosed with inoperable lung cancer:

“But of course, when anybody sort of says the word cancer, the first thing you think about is, that’s it, you’ve not got a chance in hell

.......like we always say, you can’t imagine the feeling until it actually happens.. I mean.. I’ve been through.. a very good friend of mine who had cancer.. and obviously.. I knew her since she was four.. so I mean I’ve been through that stages of it and it was pretty horrendous, but then it was a friend, not my husband.. and it obviously.. well it’s like a blood relation.. almost, well it isn’t but it is .. so obviously ... whatever Arthur was going through I was going through the same with him, to a certain extent.”
[Andrea 1 p.3]

Here Andrea is describing several elements which are typical of many of the partners of patients who took part in the study. First she equates cancer with death. She explains how the relationship with the patient is crucial to how the cancer is experienced by the relative. She then goes on to comment that she also was going through “to a certain extent”, what her husband was going through with his illness. She also explains how
one cannot imagine the feeling that you experience when your partner is diagnosed with cancer, until it actually happens to you. The feeling that the experience is beyond any anticipation of what it may be like is echoed by other participants. Debra described when her husband was diagnosed:

"people die of cancer and I just didn’t want Peter to be one of them, you know, die of such an awful thing... but... it really... I think it was harder telling people... as well, because... all I had to do, if I stopped crying, I’d look at Peter and I’d start again... how could anyone take away something that I love so much... they’re not allowed to do it... so I think I had to go off, because the more I looked at him the more I was thinking, oh my god he’s gonna die... I didn’t tell him that, but... oh it was so awful.”
[Debra 1 p.7]

Despite being assured that her husband’s disease was curable. Debra was deeply distressed. She was unable to tell her husband her great fear that he might die (see the section on ‘Protection strategies’ in chapter six for the effects that this had upon communication). Debra usually shared her worries with her husband. Feeling unable to do this and with her parents telling her that she must ‘be braver’, Debra felt very isolated by the experience. She described how she saw things:

“you’ve got a black tunnel and that’s all you can see is that black tunnel, nothing else”
[Debra 1 p.7]

In her first interview Debra described how her everyday life had been eclipsed by the knowledge of her husband’s cancer. Happily, Peter remained well and by the time of her third interview exactly two years later she said that except for a residual feeling that she remained closer to him than they otherwise might have been, the experience no longer dominated their lives:

“I feel better, because we’re coming to an end, you know like you’ve got like a dark tunnel, when people go in, and you can’t see things like... getting better. You can see them getting better but you can’t... if you know what I mean. You know that they will do, but it’s actually getting there, well we’re actually getting there now, we actually... feel so much better”
It has been shown (see chapter two, *qualitative studies about the family's experience of cancer*) how other researchers using qualitative methods (Gotay, 1984, Sabo, 1986, Davies, 1997, Hinton, 1998) have found that the close relative may be more fearful and aware of possibility of the patient's death than the people with cancer themselves. In his second interview Stephen described how he was convinced before his wife's operation that she did not have very long to live. Karen told him that she did not feel that way - indeed, although very depressed about her symptoms she does not mention this in her own interview. Norman described how he also associated cancer with death when he heard of his wife's lung cancer which he too describes as "happen[ing] to us". Like others he was unable to express his fears to his wife and he comments:

"I think the only thing I can say about the whole business ... first of all... anybody who is not associated with cancer... it's just they've been sentenced to death, to the layman... it was to me... I mean... you know... I didn't let her see that...

it suddenly hits you then you go very blank, because you think... that can't happen to us, it can't happen to us it always happens to other people, but it wasn't, it was happening to us"

A feeling of unreality and disbelief was common at the time of diagnosis. Some participants explained how this was also bound up with their fears about their own future, possibly without this person. Geoffrey explained how if he were to be truly honest with himself his real fear was for himself. He was frightened of being on his own without his wife. He felt bad about this, believing that all his sympathy should be focused on his wife who had the cancer. He should not be thinking about himself at this time:

"at that time I was really scared... obviously of her dying, because again... it's self... it's giving away to yourself. You shouldn't... just because somebody else is dying, you should be sorry for them, but no if your honest, you're worried about yourself. It comes through, if you're honest"
This acute fear did however subside as his wife recovered from surgery. Jackie described herself as being ‘selfish’ in her thoughts about Jonathan’s cancer because she did not want to be on her own again (her first husband had left her):

“I feel very sad because. I felt at first, when I first heard that this was the diagnosis, I’m gonna be on my own again, that was my first, very selfish... I was very selfish, I’m gonna be on my own again.”

[Jackie 1 p.6]

Cooper (1984) who interviewed the families of people with lung cancer, gives four possible reasons to account for why the relative may be under more stress than the patient. First, the health professionals were meeting the needs of the patient but not those of their partner. Second, others in the family’s social network may also be concentrating on the patient rather than their spouse. Third, the partners had inhibitions about expressing their own concerns and little opportunity to ventilate them. And fourth, the partners may be considering the thought of their future life on their own without their spouse - an issue which the patient themselves did not have to confront.

The participants who mentioned contemplating life after their loved one had died felt very uncomfortable about this and would want to return their thoughts to the present. However, for several of the participants - and it was usually those whose relatives had the poorer prognoses there was a degree of oscillation between ‘now’ and ‘after’, or ‘with’ and ‘without’. These relatives were experiencing what was for many the most distressing event in their life and yet they felt that to consider their own plight would be selfish and made them feel guilty.

Several participants in the study did however say that they would rather die first. Terence who had himself been successfully treated for colo-rectal cancer saw his life as not worth living without his sociable wife, who now had lung cancer.
"I felt miserable, down... right down... because I said I wanna go before her, I don’t want her to go before me... I mean that. I’ve always said that ... I said I wish it was me ... got that complaint.. I’ve said that.”
[Terence 1 p.3]

Another couple talked openly about how it was going to be worse for the one who was left behind. George who had lung cancer and was very realistic about his prognosis was desperately worried about leaving his wife on her own and she was anxious about him worrying over this:

“I don’t say I’m panicky but I get .. oh I wish it was me and not him, you know that you.. I would .. oh, cos he worries, like he says, “you know you’ll be on your own in all this””, and I say to him, well what about if.. what do you want me to do then, I’ll go first, that sort of thing.”
[Georgina 2 p.4]

In the third interview where she had become calmer she said:

“I said to him, why can’t we go together... that’s the ideal solution, isn’t it... because I’d be lost without him.. but.. that’s life Hilary, come on”
[Georgina 3 p.19]

A few of the participants actually expressed how they believed that it was more difficult to be the relative than the patient. Ivan who also had been treated for cancer himself explained how with his own cancer he felt in control, whereas with his wife’s he was never quite sure how she would react to things. He might not be able to influence her to do what he believed was best. He found dealing with his wife’s cancer more emotionally painful than he had with his own. He described the difference between being told that he had cancer himself and hearing that she had been diagnosed with it:

“Well, with your own.. I think you feel as though.. whatever it is you’re gonna cope with it, but when it’s somebody else, you feel as though you can’t. It’s like anything in life isn’t it, you always feel for somebody else.. whatever they are, whatever they’ve got.. more than what the other person does.
[Ivan 1 p.10]
Geoffrey, with a touch of humour, put this much more bluntly:

“being the patient is easy, being the relative is much the hardest, if the relative likes you, I don’t mean if the relative is waiting for you to pop off so he can inherit your fortune... that’s another idea altogether!”

[Geoffrey p.8]

It was only those married to the patient, and not the other relatives, who actually expressed the wish that it was they themselves who had the cancer. This may be explained by the fact that in the natural order of things, or family life cycle, there is a long standing anticipation that parents will die first. Nevertheless, parents are usually expected to be an important source of security well into adult life. Jane explained how, although both her parents had been ill they were both very much there still as a part of her root stability. Her father’s lung cancer - which she found difficult to think about, unbalanced this stability:

“You just think life is going to go on in its own sweet way. The routine doesn’t change, you just get on with it.. like, it’s not until something upsets that routine that it sort of brings it home to you again. I don’t know, you just think of your mum and dad.. they’re just always there aren’t they, they are just there”

[Jane 2 p.26]

Some of the female participants whose mothers had died long before the study began described that they felt they needed maternal support to provide them with comfort. Andrea echoes other participants when she describes how she wants her mother to help her through the uncertainties of her husband’s illness.

“...the mental torture of it all. But I suppose it would be nice to have someone like your mum, it’s stupid isn’t it, but it’s the comfort. You know when you’re ill at home and you’ve been a young child, and you’re mum’s there and it’s lovely, but as you get older unfortunately you haven’t got these people around you anyway. You are the person.....

it’s the security that you miss.”

[Andrea 1 p.18]
Judd (1994) described Bion's (1962) formulation of the mother as container for the infant's sometimes unmanageable feelings. Bion captures the maternal support, in part, as:

"an instinctive way of containing and processing the infant's unmanageable distress, and, in time feeding it back in tolerable form" (Judd 1994, p.88)

Several of the participants did not seem to know where they could take their own distress. They did not feel "held" or "contained" by any of their own current support systems particularly as for many the person with cancer had been the central pivot of support. Hence they were experiencing the feelings of loneliness, lack of control and fear.

Rosenblatt (1988) uses symbolic interaction theory to try to understand the effect of grief on individuals. He describes how when a significant person is lost, or in this case threatened to be lost:

"part of the social context for understanding, organising, validating, and defining feeling action, values, and priorities is removed....

Thus grief can be seen as arising not only because of a loss of a person but also because of losing part of the foundation for dealing with loss and with all of experience."
(Rosenblatt 1988, p.68)

Many of the participants in this study express in a variety of ways a profound loss of the accustomed patterns in their lives, both emotional and practical, and a deep insecurity. For many the person who had provided them with the most internal stability was the person who was causing the threat. The meaning upon which many of the participants - particularly the spouses - lives had been based was no longer safe.

**Change in outlook**

In all the participants who took part in this study there was some change in the perceptions of their world. The illness challenged the way they saw themselves and
their future and in many cases it also altered the way the relatives viewed the person with cancer as well as any outside relationships or events.

Ivan tries to explain how his wife's illness has affected his outlook on life:

"you stop thinking. you think totally different. about how you're going to attack life, what becomes important. everything reassesses itself in life. Goes from top to bottom .. bottom to top.. and probably you think about things that you might have done .. along way out.. suddenly that are at the bottom"
[Ivan 1 p.10]

This 'totally different' outlook on life is not actually articulated by many. Stephen describes giving up work to be with his wife:

"I suppose it's just a different outlook".
[Stephen 1 p.17]

Stephen implies that his priorities in life were changed, his son's outlook on the other hand appears little changed after his mother's diagnosis with cancer.

The change in outlook may be hard for the participants to see and they may not have stopped to consider it. Elizabeth described how her brother came back from the hospital with good news one day. She said she did not realise how much his illness was affecting her until its threat was absent for a while:

"I don't think you realise quite how much it affects you, um, because life goes on, it's got to go on. You've got to continue going to work and what have you. Um you don't realise until.....

I remember he came back [from the hospital] and he was sort of elated of course because they had said you know that the other cancer was finished. Um and he went out (and this is something Bernard never does), he got the mower out and he mowed the garden. I mean I always do that. He was out there doing the garden and I think just for that brief sort of weekend really it was um all the worry seemed to lift for a while and I think then you begin to realise just what it's been like for the last sort of six or so months of.... it's
with you all the time and that worry becomes part of you, um and until something like that happens and it lifts a bit, the shadow lifts off you then you realise, it makes you very much aware of what you have been living with”
[Elizabeth 2 p.1/2]

For the majority of participants there were times when they put their own needs or comfort aside to do what they perceived as best for the patient. On occasion these interventions were subtle and almost imperceptible such as surreptitiously changing their own diet to fit in with what the patient could tolerate or missing things that they had been looking forward to. In others there were more visible sacrifices such as spending time away from their own home or career or when the patient was very sick, giving themselves over totally to caring for them.

For some relatives this change in attitude towards the patient’s well-being - which before had been taken for granted, was not a consciously made decision. Andrea described how she has adapted her ways so that she is always alert to her husband’s needs believing she has a unique ability to do this:

“And .. know their moods and how they think and what’s going to make them react one way or the other... and you have to be one step ahead of it the whole time I think, really. And just get them through these bad times, the low times”
[Andrea 1 p.17]

Samantha explained how although he was relatively well she would never leave her husband on his own now. She got someone in to be with him if she ever went out (she once used the occasion of Michael’s interview - and was a long time coming back from her shopping!) She explained how she was now thinking about his well-being all the time:

“My mind’s thinking of him all the time you know whether I’ve got to keep cool and calm you know to keep him happy ain’t I?”
[Samantha 1 p.2]
Several of the participants did not live with the patient. This obviously meant that there were parts of their life which carried on without interruption by the illness. Nevertheless this did not prevent it from being in their consciousness. Judith explained:

"Because you have days where he's really bad, and in the morning I'm frightened to phone me mum .. I think oh god, how is he this morning.. then I'll phone up and she'll say .. " your father's eating egg and bacon, he's as right as rain"

[Judith 1 p.6]

Judith said she thought about her father all the time and that it was preventing her from sleeping. She explained that she rarely went out now, but on the one occasion that she went out to a dance recently she ended up talking all evening about her father to the man she was dancing with.

Not all the participants would acknowledge a change in outlook since the diagnosis of cancer in their relative. Doreen in particular claimed during the interview to be unperturbed by it. She herself had had health problems - she had been treated for a brain tumour. She also had a handicapped daughter. During her first interview she was on the verge of tears about the death of her mother from stomach cancer the year before. Her mother's illness was almost too difficult to talk about, but she was very matter of fact about her husband's cancer:

"I don’t know.. I don’t think I really felt anything in particular.. at that time .. I felt over the years that I can sort of cope with major disasters, but I can’t cope with silly things .. it bothers me ... what shall I get for dinner tonight, but that sort of didn’t worry me"

"they’d gone into it very fully.. what was going to happen and what he was going to have to do and how it would possibly affect the family.. but it hasn’t really.. I don’t think it affected me .. really. It’s been.. it did affect me in as much that.. because of his water works problem now he’s moved into the other bedroom.”

[Doreen 1 pp. 2 & 3]
The field notes following this interview are perhaps the best insight into what I thought about Doreen’s experience at the time:

“This is someone who had had a very bad time and yet she was saying, I’m a lucky woman. Having said that she was close to tears for quite a lot of the interview.. and she was sort of blinking quite a lot, although she didn’t acknowledge that she was feeling distressed. And I hope the interview didn’t make her feel that more was wrong with her husband than she thought there was. Because despite her saying take every day as it is, I felt her searching my face a couple of times, when she was talking, really looking at me for reaction... and when she gave me a lift to the station she said “he’s got to go in to hospital in a fortnight” and I sort of said... “I hope everything goes well”... and she said.. “well there’s no reason why it shouldn’t,” and I was just trying to say .. I just meant.. I hope it goes without a hitch, sort of thing, and she again repeated very ... almost aggressively.. “no, it’s going to be alright, there’s no reason why anything should go wrong”. So I wonder if perhaps she is more concerned, and I hope I didn’t make her more concerned”.

[Field notes Doreen 1 p.25]

Obviously it is crucial in the analysis of these interviews not to exaggerate the experience. This woman’s life was not as overtly affected as some of the other participants in the study. Nevertheless, despite her claim that her husband’s illness had not affected her she obviously had some anxieties about him and his ongoing treatment. She preferred not to make much of it, at least at the interview. Moving bedroom was a change which she said did not bother her, however some of the difficulties with outings and holiday arrangements - which were central to their life - were more of a declared problem.

Melvin’s agreement with his wife was that they would not mention her illness to anyone. Tears ran down his cheeks during the first interview and yet as the couples’ strategy to cope with the diagnosis was to carry on as normal, he could not really tell me that anything had changed:

“Well you pray for .. you know, that it’s gonna be alright... nothing else you can.. do or think.. you don’t think of the other side of it because .. you’ve got
Melvin and his wife were working very hard to accommodate this new 'normality' and prevent their outlook on life from changing. In the second interview he said:

"life is that way....whatever comes along, you've got to make the best of things.....

You've always got your beliefs and... it don't make any difference at all... no. I mean.. we was always thankful that we're in the position we're in and .. that's something to be thankful for.. that's the main thing."

Monica remained well throughout the interview process which meant that this couple's lives experienced no practical upheavals after the initial surgery and there was a lot of chat about holidays after the taped interviews. Nevertheless, Melvin was tearful in both interviews. This couple did not want to be interviewed a third time because they wanted to put the experience all behind them, "I think that's quite sufficient" [Melvin 2 p.13]. My field notes again comment about what I was thinking at the time:

"I don't think he does believe she's cured, he just hopes she is and is going to try and believe ..you know, tell himself that at the moment. But I was very concerned about what the whole interview might be doing to him .."

[Field notes Melvin 2 p.14]

Unlike the person with cancer, the relatives did not have to learn to live with physical changes, symptoms or treatments. The relatives also did not have an altered life expectancy. However, they did suffer a threat to self identity and potentially a damaging loss of control - features of the biographical disruption experienced in chronic illness as described by Bury (1997, p.124-5).

Bury defines two types of meaning involved in the onset of chronic illness. The first of these is about the consequences of physical symptoms for patients at a social and practical level. The relatives obviously do not experience the physical changes
themselves but nevertheless undergo sometimes quite significant practical changes in their daily life and altered relationships in their social world.

Secondly, according to Bury, meaning may also revolve around the significance of the illness for the patient. This may be more specific to the individual and concerns the symbolic significance of the disease, the metaphorical role it may play and the expectations that this may engender. The close relative of cancer patients may be particularly vulnerable to this deeper disorder of their identity.

Bury believes that biographical disruption for the patient may be mitigated in at least two ways - by explanation and by establishing legitimacy in the person's life. In this study it is harder to identify the mitigating factors for the relatives. The nature of the relatives' experiences as it will unfold in these chapters makes finding meaning for themselves in this way an unlikely element of their experience. It is possible to seize the opportunity and make the best of it, if it is one's own illness (hence the string of published accounts, self help groups, complementary therapies etc.). However, making the best out of someone else's illness is a strategy which is difficult to justify. The relatives may also find it difficult to legitimise any of their own feelings and experiences because it is not their 'right' to do so as they themselves do not have cancer.

The main mitigating factors for the relatives in this study appear to arise from the inner strength that they found to live through and manage the disruption caused by the cancer. For many their ability to care for and support the patient through the difficult times was also crucial.

Watching and waiting
A sense of not being able to do anything to change what was happening was one of the most difficult experiences for many of the relatives. For example, waiting for test results or for treatment to start and witnessing painful symptoms from the illness. This associates very closely with the feelings of insecurity. Many of the participants consciously or unconsciously took up modes of practical activities to help them live
through these difficult times (these strategies will be elaborated upon in the next chapter). Nevertheless, whichever ways the participants attempted to deal with them, the times of waiting and watching could be extremely distressing. As Jackie so vividly described:

"it's a waiting game, and in the meantime Jonathan is deteriorating. And that's the hardest thing to do, is to sit and wait, and to watch, it's a watching game. And when you see someone you love deteriorating... well it's heart wrenching, see."
[Jackie 1 p. 5]

Andrea describes seeing her 50 year old husband having difficulty walking even a short distance. He had been incapacitated by the treatment rather than the disease, but the change in his physical well-being was swift and dramatic:

"and to see him.. it was just awful, to see him trying to walk up to the hospital.. that's what makes you so... it's awful, it's just a horrible feeling to see it really"
[Andrea 1 p.11]

Melvin described watching his wife recover from surgery as the most difficult part for him:

"Well, just watching her...yes. Yes, I think.. because there's nothing you can do.. you see her.. you feel helpless in that sense"
[Melvin 1 p.5]

Some relatives said that they wished that they could bear the physical distress of the illness so that the patient would be spared from it and perhaps they themselves would have more control. To Melvin this was so obvious he did not even feel that it needed to be expressed. When I voiced the sentiment that seemed to be in the air - that he wished that he could have had his wife's operation for her replied:

"well, obviously ... it goes without saying".
[Melvin 2 p.2]
Most of the patients whose relatives took part in this study were not physically very unwell. But for some of the participants whose loved ones were physically suffering it was hard to bear. Jackie’s husband was very breathless and in great physical discomfort and she found herself actually wishing that he would die:

“I see him sitting there .. surviving as it were, and struggling, I just.. I think oh Lord what are you doing .. take him home now.. at the suffering. And I just don’t know, we’ve just got to wait and see what... we believe it’s the Lord’s purpose... whatever his purpose ... is in this, and I believe he can still heal him , right to the last breath, because the bible tells us”

[Jackie 1 p.8]

There is a tension about wanting the suffering to be over almost either way, through death or by an unexpected cure. Three of adult offspring who participated expressed their thoughts that they should actually do something to help end the suffering - although these only remained as thoughts. Jade explained:

“I’ve always been close with me dad .. and he used to say to me, “don’t ever let me get like that, do something about it”, he said “if I ever get like that, put a pillow over me face”...

[Jade 1 p.15]

After her father had died, Betty described how she had found it extremely hard to see him suffering. She explained how it was in her thoughts that if she could stop him breathing then she would have spared him a great deal of discomfort:

“I mean it’s still in mind him sitting on the sofa, I think if I could’ve put a cushion over his head and stopped him from breathing.. I think it gets so awful.. you see them in pain and there’s just nothing you can do, and you just see them wasting away and.. you know, messing the bed and wetting the bed and you just can’t ... they’re not gonna get better,”

[Betty 3 p.4/5]

Such sentiments were only expressed by the relatives of people who were very sick. These feelings were born out of deep distress at the predicament of the person with cancer and also the sense of helplessness that with their own families to look after, they
were unable to totally devote themselves to the care of the patient. Seale and Addington-Hall (1995), who undertook a large survey which, among other things, looked at people's views about the timing of the death of a relative or friend, found that spouses were more likely to say that a later death would have been better, whereas others close to the patient were more inclined to say that an earlier death would have been better. (Seale and Addington-Hall 1995). These authors believed that this was because the non spouses found care more burdensome and restrictive than those married to the patient.

Waiting for results or treatment was for some of the participants the most difficult time that they experienced. This was not usually associated with the patient being in physical distress, but living through this waiting time required substantial emotional energy whilst remaining in an essentially passive state. Andrea describes waiting for the results of her husband’s suspected lung cancer:

“And I think that time was possibly the worst, waiting..............
that period was horrendous. I think it must have been probably .. maybe only just a week, ten days, till we actually got the proper results from the [hospital], but it seemed like an eternity.”
[Andrea 1 p.2]

Stephen reported in both his first and second interview that the most difficult time was waiting for his wife to go in for surgery:

“Well, there’s no doubt that the longest and hardest time was between diagnosis and the op. That was pretty well every hour of it, we, you know just went on and on and on”
[Stephen 2 p.1]

The initial waiting for results was very intense and then for some participants the ensuing months became periods of waiting between treatment, tests or outpatient appointments. Life was shaped by anticipation of the next event in the illness trajectory. Elizabeth describes this:
“Yes... as I say... life now seems to go from you know one X ray to the next scan”

H.P.: “I remember you saying that last time.

Yes, yes and this is how he thinks - three weeks when I haven’t got to particularly worry about anything because you, there’s this gap so we can sort of get through the next three weeks, and I think life does sort of divide into these sort of “nows” set in set areas you know, and then you’ll wait for that and you’ll wait for results you might have two weeks again after that.”

[Elizabeth 2 p.12]

This change in the nature of time into pockets of waiting between illness milestones may be common to the experience of many chronic illnesses, although with cancer it may be heightened because of the fear of any kind of relapse may lead to death. The waiting time with cancer may also feel very onerous because of the unpredictable nature of the response to treatment and the lack of medical certainty about the prognosis. As Elizabeth pointed out in her first interview

“to me the thing with cancer is you hit a low point and then somebody seems to hold out the hand of hope”

[Elizabeth 1 p.16]

From Elizabeth’s point of view she was overjoyed when this happened, but in the long term it only increased the uncertainty and anxiety as her brother’s health declined. Even those who were told that the prognosis was very poor, such as George and Georgina, still maintained a hope that things might be better than predicted. Thus when George experienced symptoms, the couple were on a knife edge, hoping that these were not signs of the progression of his disease.

APPROACHING EMOTIONS

The relatives’ emotions thread through every area of the interviews. Emotions were usually expressed as a reflection of how participants felt about the particular story they were telling rather than an overall global assessment of their state. Retelling a story may
invoke different emotions than those actually felt at the time of the incident. Recollection of some events may make them feel easier with the passage of time, whilst with others it is only in retelling the story that the participants realised how painful the experience was. Thus it is impossible to say exactly how the relatives felt at a particular time and the participants’ feelings obviously may fluctuate enormously over the course of the illness.

How emotions were revealed during the interviews also depended on their relationship with me as the researcher; for example what they perceived the research was about or what they felt I could safely handle and accept. For many of the participants, the most emotional interview was the first one - retelling the diagnosis. For others it was not until they felt they knew me better that they could reveal some of their more difficult feelings. I myself often felt that I carried a heavy emotional load during data collection. I have discussed earlier the nature of the public versus the private accounts in this data (Cornwell 1984). The highly emotive nature of this enquiry led to many participants talking quite freely on our initial meeting. Where there were inhibitions or an obvious public face was maintained I have tried to indicate this in the text.

The emotions discussed here are reactions to the cancer and its repercussions. The events will mean something different to each individual depending on the context and to an extent their own psychological makeup. In terms of psychological assessment, emotional distress has been shown to be greater for the relatives than the patient (Harrison et al. 1995). This is an indication that the relatives of cancer patients merit attention but, as these authors comment, it does not identify who needs it most. The cultural influences on emotion have been explored by sociologists and anthropologists, but emotions are complex and remain difficult to write about - whatever the discipline. Klienman (1995), writing as a medical anthropologist, elaborates this dilemma:

“Nor is it morally superior to anthropologize distress, rather than to medicalize it. What is lost in biomedical renditions - the complexity, uncertainty, and ordinariness of some man or woman’s world of experience - is also missing when illness is reinterpreted as social role, social strategy, or social symbol.... as anything but human experience” (Klienman 1995, p.96).
Klienman goes on to explain that he is not arguing that suffering should be ‘taken neat without its cultural meanings and historical changes’ (p.96) but he is warning against being ‘experience-distant’ (p.96).

The relatives in this study indicated their emotions in many ways. It was often difficult for them to say exactly how they felt - sometimes it felt very superficial even to ask them to explain what was implied. Many of them did not appear to have spent much time considering their own emotional experience so focused was their attention on the person with cancer.

Ivan, in his first interview was actually able to articulate how difficult it was to describe or quantify distress:

“I don’t think you really accept at what level you’re worrying at... you know.. if you had a gauge, 1 to 10, you probably wouldn’t know where you were on it... the average bloke wouldn’t”  
[Ivan 1 p.]

For some participants this may have been because their feelings were just too painful to focus on. One of the relatives who felt that she could not take part in the study was the wife of a man with advanced colo-rectal cancer. She was obviously very distressed but explained that to talk about her own feelings at such a difficult time was not possible for her. Her priority was to keep herself going in order to look after her husband.

Emotions are difficult to talk about, difficult to put into words and sometimes difficult to admit to. Some of the people who took part in the study were obviously working hard to stop themselves considering how upsetting the situation was. The relatives expressed varying levels of awareness of the ways in which they prevented themselves from fully feeling their distress. Jill explained about how she reacted when Jack had to go into hospital to have his lung removed:
"But ... I can't believe it until it happens like, you're gonna be alright. nobody's gonna... it's just my way, I suppose I sort of bury me head in the sand a bit really cos quite honestly you, you don't believe it's gonna happen until it does. I suppose that's really. I mean inside I was deep down sick with worry."

[Jill 1 p.11]

Again an excerpt from the field notes reveals more than can be seen on the page of the transcribed interview,

"Almost all the way through the interview she had tears in her eyes and tears just running down her cheeks... although I'm sure this probably doesn't come out on what's recorded at all, because her voice didn't waver, and she kept on talking. But all the time she just had... very.. tears right down her cheeks."

[Field notes Jill 1 p.13]

The interview process itself at times revealed the depth of sometimes previously unexpressed emotion. The interviews were often very emotionally charged and the majority of the relatives were tearful at some point during the research process. In the first interview with Georgina the tape recorder had to be turned off for some time. She was explaining how she thought that her husband was losing weight because she had put him on a diet

"So I said I'll cut you down and I didn't realise... you see cutting him down and didn't realise he was losing weight through ... the cancer (voice tearful). Sorry, so I felt a bit to blame."

(Tape switched off here.)

(Recording resumes)

"We had his brother come round. he comes round every Wednesday."

[Georgina 1 p.2]

Georgina was enormously distressed but at this time she could not express the emotion, where among other things she was obviously feeling very guilty, except through her tears. When talking about the situation she attempted to remain matter of fact and talk about events. It was too overwhelming it seemed for many participants to actually allow
themselves to let go and feel what this meant. The use of denial as 'an unconscious refusal to acknowledge certain distressing aspects of reality' (Barraclough, 1994, p.59) has been fully elaborated in terms of the ways in which this is utilised by people who have cancer (Barraclough 1994). Relatives on the other hand may be more conscious about the patients' deteriorating condition, however, in order to continue to support that person they may feel that they cannot let the outside world know of their recognition and feelings about this, except under very special circumstances. This is not denial as such, but is a way of managing their emotion.

Hochschild (1983) in her book 'The Managed Heart' explored the notion of the commercialisation of feeling, and how human emotions may be need to be managed in some areas of professional work, such as in the case of air flight attendants. Hochschild describes how life inevitably involves a certain amount of 'acting'; 'surface acting' – which is when we try to change how we outwardly appear, and 'deep acting' which she describes as 'trying to feel what we sense we ought to feel or want to feel' (Hochschild 1983, p.43). There is a very strong sense in the interviews that majority of the participants feel that they must keep some control over their emotions – at least for most of the time, which as Hochschild comments may create two barriers – to reflection and to spontaneous feeling. Jade explained how she could only permit expression of her grief in circumstances that she felt were safe for her:

"but saying that, it's very hard, it's hard to keep a normal life going.. two children, run a house.. I run everything, the money, finances.. my husband goes to work that's it. I deal with everything else and I found that really hard.. I couldn't... I think the only time I cried... cos I think you have to pick your times to cry.. to feel sorry for yourself.. oh why does this happen to me? I won't do it in front of people.. I won't do it in front of my husband.. he finds that very hard to understand.. I'll put on a hard front, because I like to grieve on my own, not in front of people. And people look on it that I'm hard, but I'm not. I just deal with it differently.. I like to be on my own... I might even sit down and get through a bottle of sherry at 2 o'clock in the morning, and then crawl up the stairs but I'll do it on my own, in my own time.. not when I've got things to cope with that I think I must do."

[Jade 1 p.7]
Andrea who described herself as being “tough” in order to get her husband through the illness, also talked about how she found an outlet when she was really on her own without any responsibilities:

“when I was on my own, took the dogs for a walk, which I do every morning. I’m out in a field, and it’s all quiet and you think.. I was just terrible. I used to have awful sort of sessions.. tears running down my face.. and quickly used to wipe them before Arthur could see me... because you’ve got to put on this very brave front the whole time.”
[Andrea 1 p.5]

The majority of people who took part in this study were at great pains to protect the person with cancer from any additional worry, particularly relevant here are the attempts to prevent the patient from witnessing the relative’s own distress about the illness (see Protection Strategies in the next chapter). This did not apply to everyone, Robert expressed a view of cancer which was different from that of other participants:

“I can’t be bothered really.. to be quite honest. There’s no point in getting vastly worked up. So I don’t think I did.”
[Robert 1 p.6]

His view of cancer is different form other participants as is his professed attitude towards his mother’s illness, perhaps reflecting his age and the fact that he was away at boarding school. He does not describe himself as “burying his head in the sand”, but rather as not really feeling anything about the illness at all. His parents were very careful to protect him from seeing their anxiety about the illness and perhaps they were very successful.

Julia’s interview was also different from others in the study. She herself had severe chronic disability. She was not initially told her husband had ‘cancer’, but rather ‘tumour’ and this word did not have the same impact on her:

“and it didn’t sink in at first. To say a tumour is different to turning round and saying he’s got cancer, you know”
[Julia 1 p.3]
Julia's husband was very sick when I interviewed her. The interview was very difficult (for me) and I found it hard to make sense of because Julia was at times very vague. Yet at one time she discussed quite lucidly renting out the rooms upstairs after her husband had died, appearing quite matter of fact about this. Subsequent interviews with her daughters in which they revealed some of Julia's own medical history threw a degree of light on this. It seems Julia's history of health problems made it difficult for her to engage with what was happening with her husband.

Doris on the other hand was able talk more freely about her feelings. During the course of her three interviews she articulated the emotional roller coaster of living with her husband's cancer. She could describe the lifting of her spirits on the days when her husband was feeling better and thus giving a hint about how bad it was when he was poorly:

"I have the times when I think "Oh he's better, he's much better" and then it's lovely, and then I'm not all tight and tense and miserable and wonder whether life's worth living you know"

[Doris 3 p.9]

Participants experienced the full range of painful human emotion. Several described themselves as feeling guilty that they were not doing enough or the patient. The interview with Jane who looked after her father with lung cancer and saw him virtually every day was riddled with her expressions of guilt.

"I feel terribly guilty"

[Jane 2 p.11]

She felt guilty that she was not doing enough for her father, guilty about neglecting her husband, her children, her job. Anger was another difficult emotion, which was in this study was most frequently aimed at the health care system (see chapter seven). Surprisingly perhaps participants expressed little anger towards the patient for the upset they had caused to their lives. Several mentioned how they now made great efforts not
to argue with the person with cancer (see Protection Strategies). Although smoking had presumably caused ten of the cancers in this study sample, there was remarkably little mentioned about this. This is a similar finding to Cooper's (1984) study of family relationships and lung cancer. Cooper comments that possibly some partners may have had suppressed anger about the smoking but felt it would be 'an unseemly emotion to express under the circumstances' (Cooper, 1984, p.306).

PHYSICAL MANIFESTATIONS OF EMOTIONAL DISTURBANCE

Some participants were able to vividly recall and describe the physical manifestations of their emotional upheaval. This seemed sometimes easier to put into words than recalling the emotions themselves. In some instances there were striking similarities between participants, for example, in their descriptions of hearing the diagnosis - whatever the implications of it were. It seems that their body could physically register the shock before their mind could begin to process what was happening.

Ivan talked about how he felt as the full extent of his wife's diagnosis unfolded. He describes how he felt he was being assaulted himself:

"I felt as though something had been stuck inside me.. a knife or something, I don't know. That was the piercing blow I think....

it was as though I had a sword stuck in me. It was like.. that sort of feeling you get when.. as though you're going to pass out.. that hot feeling, it goes right inside.....

You know sometimes.. if you've ever passed out, and you get that feeling inside.. a weird sort of sensation, just before you're gonna go, most peculiar sort of sensation, well it is a shock isn't it, basically.. the systems been shocked, in't it"
[Ivan 1 pp. 3-5]

Samantha had no inkling at all that her husband might have bowel cancer:
“so he went and had his check up .. I said, “how did you get on?” “I got cancer of the bowels” I said. you’re joking.. I thought he was kidding me

Oh, I was all over the place, I had the jitters, me legs was going up and down.. and ... they couldn’t calm me down”
[Samantha 3 p.11]

Anne described how she and her husband were given his diagnosis of lung cancer:

“Then he said ‘well, the tests...It’s cancer’, and he said ‘you’ll have the support of the hospital and your family’. And it seemed like the crack of doom like, you know.. we both just sat there and .. I sort of put a glance at him and we just sat there like two mutes, and he said [the doctor] ‘if you want to ask any questions and that’....

Well I was thinking ... I didn’t know what to think.. I couldn’t swallow.. we both.. mouth went all dry.”
[Anne 1 p.1]

There are several examples in the research where participants say that they were rendered speechless by hearing their relative’s diagnosis. This is often at the very time when health professionals are hoping that patients and relatives will be taking in this new and often quite complex information and formulating questions about what they have just been told. Melvin describes his reactions to hearing his wife’s diagnosis

“it takes the wind out of you...yes you’re lost for words

Shocking.. .. couldn’t speak for a long while”
[Melvin 1 p.7]

Lupton (1998) comments that the bodily experience of emotions may be described as ‘the body coming to the fore, making itself known, slipping beyond the bonds of the mind or will’s control’. (Lupton 1998, p.95) . Rose described hearing that her mother had lung cancer

“the stomach drops out of your body, and you think.. oh heavens .. how can this be.”
[Rose 1 p.4]
If I did ask participants how they felt they often interpreted this as meaning physically rather than emotionally. As Judd (1994) comments:

“The degree to which both physical and emotional resources become overwhelmed is a clear reminder that the effects of a traumatic experience cannot be separated into body and mind” (Judd, 1994, p.91)

For most of the participants the diagnosis was the time of greatest emotional impact and the initial feelings of being physically shocked which many experienced on hearing the diagnosis did resolve with time. However, for some there were longer term chronic health problems, particularly associated with sleeping or eating. At the first interview, over half of the relatives indicated in the post interview questionnaire that their sleep was disrupted, and exactly one half (of the smaller sample) still had sleep disturbance at the third interview. Eleven out of twenty six relatives reported the patient’s illness having an impact on their own general well being at the first interview with a half reporting this at the final interview. Exactly half the relatives at the first interview reported that their eating had been affected by the illness - many of them lost substantial amounts of weight (except one participant who had stopped her diet and put on three stones). By the third interview however, eating habits were reported as having returned to normal.

Sabo et al (1986) who interviewed the husbands of women with breast cancer found that they reported increased moodiness, loss of energy and growing fears about their own illness and death. Sabo attributes this to the fact that the men were denying their own feelings and placing those of their wives in the foreground of their thoughts - this denial of their own emotions thus intensifying their deeper anxieties. This may be reflected in the findings of an early psychiatric study that found that only 7% of the husbands of women with breast cancer who were distressed had discussed their fears with anyone (Maguire 1981).
Here, this common experience of finding it difficult to express feelings seemed to be compounded for the family by believing (as will be illustrated in depth later) that, as it was the patient who had the serious illness, the relative did not have the right to express their own emotional reaction to the situation. At a time when there is a prevailing belief that it is healthy to express emotions, many of the participants corresponded to the expectation that emotions will be ‘managed’ to conform with the social situation (Lupton, 1998). In this study the lack of opportunity to express emotion may have taken it’s toll physically. As Jade explained:

“But I suppose really your health does deteriorate, you feel tired, you feel irritable, in my case you lose weight, you find it hard to put it back on, you’re tired, but you can’t sleep, and it does catch up with you in the end”

[Jade 1 tape 2 p.28]

And Rose explained about her difficulty with sleeping:

“I suppose about 3 or 4 times a week probably .. I’m awake at 3 o’clock and then everything crowds in.. you think... oh Christ here we go.. I’d better read a book quick, before it... so I mean the stress is there, it’s just.. one manages to keep it under control most of the time.”

[Rose 1 p.17]

Several participants comment on how empty their home was when the patient was in hospital - this deep loneliness perhaps perceived as a foretaste of life to come. Terence who was usually adept at managing domestic affairs described his home when his wife was in hospital:

“What was it like? Like a mortuary.. fed up, I hardly ate, I hardly cooked anything. Well I didn’t fancy it, know what I mean?

Did you sleep?

No. Even that whisky there, one night I had a good douse of it, didn’t make no difference”

[Terence 1 p.7]
Terence later told me about his worries about his wife’s weight loss - she had lost 10lb. Terence was concerned that the cancer had caused this. When I subsequently asked him about his own weight it transpired that he had lost a stone, which he put down to being “the worrying type”.

Stephen described his own physical experience of his wife’s symptoms which he attributed in part to tension, but also to feeling her physical discomfort with her:

“I have on more occasions than not had a feeling of stomach pain”
[Stephen 1 p.]

This was the only instance of ‘phantom symptoms’ expressed by participants in this study.

BECOMING ACCUSTOMED TO LIVING WITH CANCER IN A CLOSE RELATIVE OR FRIEND – MINIMISING THE THREAT OF THE ILLNESS

Thirteen of the relatives who took part in the study were interviewed three times over a one to two year period and in one case this stretched over three years. Five relatives were interviewed twice, the rest once. The trajectories of their experience with the illness varied considerably for a number of reasons - the different diagnoses, stage of illness and treatment of the patient and the assorted relationships and social circumstance of the participants. The analysis of these interviews has thus not led to the description of stages of the experience because this study did not reveal a predictable time pattern.

The overall impression from the interviews was that although many of the participants experienced the initial diagnosis as deeply distressing they were all able to live and function through it. The majority regained some kind of stability quite quickly. Some felt that they were able to become quite emotionally strong and resilient and able to support the person with cancer. Many felt that they coped better than they would have
anticipated - although in the longer term this could become very wearing. Andrea described the week after the diagnosis:

"But I think actually, it's funny.. over the period of the week... it seems to wear off, not because you don't feel the same things, cos you do, but I think you almost become hardened to the problem... because you have to face it the whole time.. and you have to try and carry on life as it used to be, within the realm of reason."

[Andrea 1 p.5]

Jackie, speaking about three months after hearing the diagnosis described her state:

"I'm more stable now than what I was at the beginning of finding out."

[Jackie 1 p.9]

With time the cancer itself could become easier to talk about. Melvin who had been unable to mention the word in his first interview was able to say "cancer", a few months later. Norman commented:

"Funny bit, you can talk about it, can't you.. I don't think we either liked to talk about it too much initially."

[Norman 1 p.11]

Doris who did find living with her husband's illness very difficult believed that it had forced her into doing things which she previously felt unable to do, and she was pleased with this:

"Well it's made me tougher, I'm much tougher, I used to be so soft... that's what he said... that I used to... I've still got compassion"

[Doris 3 p.6]

Elizabeth thought quite carefully about her responses to her brother's illness. She, like Doris, was pleased with the way she had managed to do things she had felt she could not manage before - such as driving the car. However, in this extract from her third interview she explains how this sometimes makes her feel:
"You do feel guilty and I suppose really if you’re very honest with yourself after a while (and this is the hardest thing in the world to say) you resent illness. And this sounds awful but... when someone’s ill for a long time like that you do somewhere deep inside you begin to think, you know, um, you’re never going to get better or, um... It’s hard to explain, I suppose it’s almost an intolerance after a while which you then feel terribly guilty about.”

[Elizabeth 3 p.2]

The long term uncertainty of the illness along with not being able to get on with her own life - she was a young woman and until the cancer had lived independently of her brother - had taken a toll on her emotional and physical reserves.

Coping is a word commonly used in everyday exchange. It is more problematic to use in academic writing partly because, as Bury (1997) points out, it has associations of ‘successful’ and ‘unsuccessful’ responses to a situation (p.130) and partly because it is difficult to clearly define as it may cover such a multitude of ways of dealing with life. Bury (1991) defines coping as ‘the cognitive processes whereby the individual learns how to tolerate or put up with the effects of illness’ (Bury 1991, p.460). Some of the participants in this study may have described themselves as coping with a situation which they actually found intolerable. And yet they all do find ways of living with or getting through the difficult times.

Corbin and Strauss (1988) are concerned with the human costs accrued by the ‘continuous accommodation’ couples make in response to illness:

“By accommodation we mean the day-to-day struggle of spouses to keep some sense of balance and give meaning to their respective lives as they attempt to manage a severe illness. This struggle involves a constant juggling of time, space, energy, money, jobs activities, and identities.”

(Corbin and Strauss, 1988, p.6)

Most of the participants in this sample responded to the illness by making some changes to their approach to life. Some of these changes might be practical ‘juggling’, for example Jade and Judith’s care for their parents or Rose’s time away from her family to be with her mother. These, sometimes fairly significant, practical adjustments were
aimed at minimising either the emotional or the physical disturbance caused by the cancer. Other changes were less obvious and were more to do with a change in the way of thinking about life and illness.

Described below are some of the means by which participants managed their lives in order to lesson the threat posed by the cancer. They are not mutually exclusive and by some relatives they were used in tandem, whilst by others they were not used at all. As Salander et al (1996) comment nothing can be done to change the reality of a life threatening illness:

"Faced with a cancer diagnosis, the person becomes a patient, every-day life is disrupted, and in order to survive mentally s/he has to rely on cognitive ways to manage his/her emotions" (Salander et al. 1996, p.985).

In Salander’s study the focus was on the patients, although partners were also interviewed. These partners were found unable to ‘create protection and hope to the same extent as the patients’ (p.994) and because of this they are described as ‘extremely exposed’ (p.995). This is consistent with the findings of this study. However, Salander’s population of patients were diagnosed with cerebral glioma with an invariably poor prognosis and furthermore the respondents were interviewed within the first two months after diagnosis. Thus in this earlier study there had been less opportunity for participants to reframe the situation than in the research discussed here.

**Carrying on as normal**

Several of the participants described trying to carry on as normal as one of the ways they found to live with the cancer. Anne comments:

"Yes, sort of carry on normal, not keep thinking about it"

[Anne 2 p.2]

This again, was a way of preventing the cancer from intruding into their lives any more than it had to, and keeping it at bay. Life for many of the participants had been severely disrupted and there seemed to be a need to maintain some order in these potentially very
disordered situations. This was in many respects filled with contradiction - because life was not quite as “normal” as it had been. The Cornwall family were determined to carry on with Christmas as normal - although Karen was about to have major surgery for a life threatening illness. Georgina described how she saw it at her second interview:

“honestly can’t say I think about it.. really.. it’s not on me mind all the time, which in a way I think is a good thing. You know, we’ve just been living our life as we did before... it’s just.. to watch him, if he overdoes it.”
[Georgina 2 p.17]

Corbin and Strauss (1988) describe normalising as a way of living with chronic illness, and several authors have described this as a strategy adopted by the close relatives of people with cancer (see Thorne, 1985, Hilton, 1996, Rose, 1997 in the section on qualitative studies about the family’s experience of cancer in chapter two). In this study, except for those where the patient was dying, there seemed to be a need for the majority of participants to attempt to carry on without making any dramatic concessions to the illness. As in Rose and colleagues’ (1997) study these participants revealed a spectrum of efforts of being ‘normal’ and this enabled the families to function. For those where the patient remained well, as with Debra, life did largely resume its earlier course. For others, for example Monica and Melvin or Daniel and Doreen had to ‘work’ very hard at this. Others such as Nora and Geoffrey found keeping life relatively normal a prolonged exercise into which Nora as the patient in particular put much effort.

For the majority of the participants in the study however, particularly in the first few months after the diagnosis, what might appear as normality on the outside was not the same as it had been before. This experience unlike other changes in life, a marriage or a new job or even death was something which potentially created an ongoing and forceful internal uncertainty.

*Lucky factor - social comparison*

The discussion of the Cornwall family showed how members of this family made comparisons with those perceived to have greater misfortune. Whilst interviewing the
families in this study I was surprised at how many of the participants commented on how much better off they were than they might have been in other circumstances. Jade described how she used this as a coping strategy:

"I’m a lot luckier than a lot of people.. my husband is a worker.........

there’s a lot of people that have to go through a lot of stress, a lot of grief, but with nothing, living on the breadline.

Everything I think in life I think can be worse, so I look at it that way. Sometimes it works for me sometimes it doesn’t.”

[Jade 1 tape 2 p.20 ]

Others also appeared to take on this way of thinking. Earlier Melvin described himself as ‘thankful’. Salander et al (1996) describe ‘displacement or downward comparison’ whereby contrasting one’s own despair with someone worse off reformats a bad situation into a better one, creating some protection from the experience. Samantha commented:

“there are people worse off than us”

[Samantha 2 p.18]

Jackie tried to reframe the experience by thinking how lucky there were to have had a good relationship:

“we still had a pretty reasonable good life”

[Jackie 1 p1]

Andrea also described her way of looking at her husband’s illness, although appreciating how lucky she was, this also made her realise how much she had to lose:

“as I say nobody knows how long anybody is going to live.. so I think when you’re faced with a problem, I think you have to look at it in a different way

it does make you appreciate what you’ve got and what you’ve had ....and how awful it would be to lose any part of that really.”

[Andrea 1 p.14]
Living with thinking that this is the worst thing that could happen might be untenable. These views were thus not necessarily a result of optimism but a way of providing some comfort to keep on going.

**Keeping going**

Keeping going is closely linked with sections in the next chapter where the notion that the practical activity created by the illness may also provide a way of coping with, or getting through the experience is explored more fully. This was not a way of thinking more positively about the situation - perhaps more of a distraction technique. Andrea explains this very clearly:

> "I feel I’ve got to be doing something the whole time... when I actually stop.. I think... I will fall into a heap and just disintegrate"
> [Andrea 2 p.15]

There seems to be a worry amongst some participants that if they did stop and think about what was happening then they would not be able to cope. Samantha describes how she believed she prevented herself from having a ‘breakdown’:

> "You got to keep going all the time you’ve got to keep cheerful. It’s no good looking, you know, being down, because you could put yourself right in a state that you’d have a breakdown yourself wouldn’t yer. No I’m jolly me, I keep myself going".
> [Samantha 1 p.3]

Samantha comments that it is “no good looking”, which may be seen as a form of denial of the difficulties of the situation. Nevertheless, both of these women have a fairly clear idea about what is going on but choose strategies which preclude them from dwelling on this when they do not want to. Indeed, we saw earlier how Andrea chose the times when she felt she could allow herself to be in a “heap”.

Again the participants who this did not apply to were those who themselves had poor health - Geoffrey and Julia, and also Robert who only made very minimal changes to his way of life.

These ways used by some of the relatives to minimise the impact of the cancer also served to minimise any expression of feeling about the illness. For several of the participants it was the interview process itself which provided the opportunity for this. They had previously had little opportunity to tell their own story.

THE PARTICIPANT’S ACCOUNTS

This study is made up of the participant’s stories which were told to me for the purpose of this research. The majority of people who took part in the study, although sometimes initially embarrassed, seemed motivated to talk, often at length, about what had been happening. Nevertheless, the relatives often recounted issues that were salient for the person with cancer rather than their own experiences. Indeed, there was some difference in style between the transcripts of the patient interviews and those of the family. The patients tended on the whole to provide a more direct description of events, and although it was frequently difficult, they were telling their own story. Many of the relatives gave less focused interviews. Even those most distressed about the illness and who talked about it in terms of “we” and “our”, did not give such a clear linear account as the patients. The relatives seemed to find it hard to think clearly about their own experience. Some of them could hardly see the point of doing this research at all as it was the patient’s concerns which were paramount.

Those who were less involved in the day to day life of the person with cancer sometimes found it the hardest to focus. They were often telling multiple stories. For example Jane talked for nearly 45 minutes about her own post natal depression and Jade talked at great length about her father-in-law’s suicide. These interviews emphasised the fact that these people were often attempting to cope on more than one level with what was happening in their lives.
Good (1994) describes how the narrators of most illness stories, be it patient or close relative, are invariably in the middle of their story. There may be many independent stories within the larger episode of the illness and the narrator may not make any attempt to establish a relationship between the stories told or select a single coherent narrative. The stories may have gaps which are unspoken and unexplained. The story may well present contradictions; for example, as in Jackie or Jade’s case, the desire for the patient’s suffering to be over with and the wish that they would continue to live for a long time. Or as Andrea commented they were:

“told from the beginning that is it, you have not got a chance at all, [but] you always think there’s a chance, there’s no doubt about it.”
[Andrea 2 p.3]

Nevertheless, Good (1994) comments that while narrative representations of illness provide insight into the nature of the illness experience, they represent illness in a life - whereas ‘disease as represented in biomedicine is localised in the body, in discrete sites or physiological processes’ (Good 1994, p.157).

The participants in this study were in the middle of their stories. However, there was a difference between those who were still ‘living with cancer’ and those who had been bereaved, the latter had experienced an ending of sorts. Alison who was interviewed only after her mother had died gave an account that was much more specifically about her own concerns than many of the other participants. Those interviews conducted after the patient’s death became much more clearly the relative’s own story. Here, they appeared to feel less inhibited about expressing their emotions. Their grief seemed to be perceived as legitimate now that they were the people who were suffering. As with the published accounts about the experiences of cancer, it is perhaps easier for the relatives to recount their story from the perspective of after the death than whilst they are going through the experience. Edgar, writing in The Guardian newspaper after his wife’s death from lung cancer comments: As Nietzsche said, “life is lived forwards but understood backwards” (Edgar 1999, p.2)
**Close recall of significant events**

There were several common features about the style of telling the stories. One was that despite a lack of clear structure in many of the interviews, when retelling the significant events, such as the time of diagnosis or death there was often a very detailed recall of what happened. For example in the interviews after the death of the patient, the details around the time of the death had to be carefully recalled. Andrea remembered exactly what she was doing in the minutes before Arthur collapsed and died:

> “I went and had a shower... and I came out of the shower and I said, “how do you feel?” and he said “not too bad”.

[Andrea 2 p.5]

And Jackie recalls the moments before her husband’s death:

> “it was a chicken flavour .. a mug of the soup ... so I put that down and he said .. “it’s a little bit chilly now, I think I’ll get into bed”, so I said alright then, I’lI help you swing your legs round ... this was about five to six... and he said “cor, I feel funny”, and I said “do you” and he said “yes”... and then he started to cough again”

[Jackie 2 p.6]

Nicholson (1997) in her study of the narratives of people facing death comments, ‘Finding meaning is a continual process as experiences are incorporated into the existing life story. This is not easy and may require revisiting the same experience an infinite number of times’ (Nicholson 1997, p.19). Nicholson describes the ‘unnecessary detail’ with which the participants in her study elaborate their stories — ‘as if remembering something very clearly can help in making sense’ (Nicholson, 1997 p.21). As Edgar again comments, ‘No event is humanly complete unless it has at least the possibility of being re-experienced by telling’ (Edgar, 1999, p.3)

**Putting this experience in context**

For several of the participants this was the first time they had allowed themselves - or been allowed - to tell their story. Taking part in the study and talking about their
experiences of having a close relative or friend with cancer prompted many of the participants to also talk about the other difficult areas in their lives. Talking about the emotional disturbance created by the cancer could not be thought about in isolation from other personal difficulties. The relatives appeared to be attempting to contextualise this current situation in some way by fitting it in with the thread of their life. Comparing their reactions to this experience with other difficult and sad times might allow the relative to acquire some further understanding of themselves. Jade’s account of her young daughter’s accident took four and a half pages of interview transcript, Jade said it was:

“the hardest thing that I’ve ever had to cope with .... out of all of it, the suicide would be second ..

[Jade 1 tape 2 p. 16]

(Her father-in-law committed suicide when her mother-in-law became terminally ill with cancer - this took three pages of interview transcript). Thus her father’s cancer was not the worst thing that Jade had had to cope with.

Norman described the death of his son:

“taken ill and died in a week...ten he was. That was dreadful, you never get over it,

There’s always a part of you missing”

[Norman 1 p.13]

Norma and Norman had both led very eventful lives. There was a certain pride that they had come through this:

“I wish I could write, because our courtship and marriage would be a best seller wouldn’t it?”

[Norman 1 p.11]

Jill talked at length about her husband’s death from cancer, the experience of which she felt helped her deal with Jack’s illness and death. Mathieson and Stam (1995) argue that
life's events must be articulated in a coherent story. In their interview study with people with cancer these authors describe how a new life story has to be found which would incorporate the meaning of the illness. Jane experienced her sister-in-law's sudden death from cancer during the study period, and this made her reflect on her own view of life:

“I suppose like my sister in law going so young, it's hit home that you're ... you know things just don't run to the general ... like your nan goes first, your mum then follows and it happens like that. That has hit ..”

[Jane 2 p.27]

This traumatic disruption of the natural order of things made Jane think about who would care for her family if anything happened to her personally. Mathieson and Stam (1995) comment that “having cancer redefines this social space, disrupts intimate relationships, and generally reorganises the ‘geography’ of social functions” (Mathieson and Stam 1995). These authors, arguing from the point of view of the patient comment that relationships have to be re-negotiated from the changing positions created by the illness.

Several of the participants used their experiences of the war as reference points. In particular Melvin and Anne talked at length about their life during the blitz - although unfortunately this was after the tape recorder had been turned off. Anne still seemed very burdened by the death of her niece for whom she was responsible, during an air raid. The interview with Geoffrey was interspersed with stories about the war - he was a pilot during the second world war. As he comments:

“Well to our generation, the war was easily the most influencing ... thing there ever was.”

[Geoffrey 2 p.5]

Geoffrey describes this in relation to his wife’s illness

“it’s funny, you forget the past, not that you forget the past, the past was very.. usually ... very boring, with tiny incidents, or tiny periods of over
excitement and sheer panic. But you never really forget it. And therefore when you started talking about... when you’re suddenly hit with the feeling of: this is really going to actually hurt me...........
[Geoffrey 2 p.5]

In his study of Alcohol Anonymous groups Steffan (1997) found that within the group ‘the narrator’s experience of pain and suffering loses it’s meaninglessness and gains value as collective knowledge” (Steffen 1997, p.106). The telling of the story is a process which helps both the narrator and the listener who is caused to reflect on their own experiences and in turn add to the narrative.

The difficulty for the relatives who took part in this study was that for many of them there had been little chance to tell their own story. This was not only because it was the patient’s story or history which was of paramount concern, but also because they were – partly because of this – not in a position to construct a coherent linear story of their own in relation to these ongoing experiences. This was a central feature of the accounts recorded for this study.

Finding meaning
Williams (1989) elucidates ‘narrative reconstruction’ as a ‘typical’ process found to a certain degree throughout his study of a group of people with rheumatoid arthritis. Williams describes how ‘the individual’s narrative has to be reconstructed both in order to understand the illness in terms of past social experience and to reaffirm the impression that life has a course and the self has a purpose or telos’. (p.270). He writes:

“If the prime sociological importance of chronic illness is the ‘biological disruption’ to which it gives rise, then an individual’s account of the origin of that illness in terms of putative causes can perhaps most profitably be read as an attempt to establish points of reference between body self and society and to reconstruct a sense of order from the fragmentation produced by chronic illness.” (Williams 1989, p. 269)

Williams interviewed ‘seasoned professionals’ of chronic illness rather than ‘novices’ for his study. In this current research the participants, certainly on their first and second
interviews were very new and raw to the experience. Narrative reconstruction involves a number of elements including genesis and understanding. Some elements of this notion of narrative reconstruction are relevant to the participants in this study. But this notion also illustrates a difference in experience between being the relative and being the patient.

Some of the relatives did look for explanations for the patient's illness, for example through eating an unhealthy diet or smoking. A few participants mentioned their concern at the amount of stress that the patient had been under. On the other hand there were also comments about how they were finding the cancer diagnosis difficult to make sense of because the patient was never usually ill and had had such a healthy lifestyle.

With the cancer illness itself there is something to find an explanation for which may help understanding and finding ways of living with the illness. However, it is more difficult for the close relatives to begin to find reasons why they should have the experience of someone else being diagnosed with a life threatening disease. In some senses nothing has happened to them - it has happened to somebody else. The relatives may get some form of understanding by setting this experience against other difficult times in their past. But, it may feel too uncomfortable to turn this into a reason to re-evaluate their life in a positive way. Finding any purpose for themselves in a loved one's misfortune is unpalatable. The relatives do not face the potentially creative challenge of finding ways to keep living. Taylor (1983) believes that elements of the search for meaning involve understanding and explaining the cause of the distress. In her study, 95% of her sample of 78 women with breast cancer as opposed to 63% of their partners offered an explanation of what had caused the cancer (Taylor 1983).

In many ways the relatives' experience appears to be more a constant series of readjustments to their life and interactions with the patient with little sense of purpose in the experience. Ivan illustrates this most clearly. He described his life at his first interview:
“Yes, I think I’m going to be on hold for a year. I feel ... there’s nothing really in life... that I’ve done has any real meaning at the moment... and I’m waiting, just waiting the same as she is, for the year to end. Counting the weeks off, and hoping that at the end it’ll have done its job like, you know. I mean if it’s done it’s job at the end of the year, hooray... But I think we’re all gonna come out different, undoubtedly...”
[Ivan 1 p.8]

He does believe that they are all going to come out differently, but at this time there is no of meaning or purpose in this for him. In the third interview with Ivan there was no still sense that he had been able to reconstruct his life to find understanding or meaning:

“it all keeps going back to square one .. you don’t feel as if you’ve gone on, moved on, I think you’re living in limbo land all the time it’s going on, and you don’t really live your life do you? You just live from day to day, I think”
[Ivan 3 p. 5 ]

However, when I interviewed his wife the patient, she had a very sophisticated explanation of the genesis of her cancer and how this fitted in with her life pattern.

Samantha who herself was diagnosed with a brain tumour during the study felt she could explain the origins of her own illness in how she had stuck by her son and supported him through his bouts of drinking violence and stretches in prison:

“I thought .. that’s what made me ill half the time, worry”
[Samantha 3 p. ]

But she could not explain why she had to suffer her husband’s illness.

A few of the participants did comment about how their life might be in the future if the patient died and what this would mean for them. This kind of preparation has been described as anticipatory grief (Parkes 1975). This is expressed clearly here by Elizabeth, who reconstructs her life without her brother:
"you think... what would I do if I had to drive all the way on holiday, how would I cope.. you know if something goes wrong with the electrics, or with the house..................

Terrible as it is, your life has to go on, and it's more or less the way of mentally preparing for the time when maybe that person isn't there, but it does make you feel awful"
[Elizabeth 3 p.3/4]

A small number of participants used a religious framework. Jackie creates order in the destruction of her life through her evangelical Christian beliefs:

"I don't know, but .... all I know is that somewhere along the line, there's a reason for it, and one day when we get there He will tell us why this is being allowed."
[Jackie 1 p.6]

Nevertheless when Jonathan dies her faith does not initially help her. Jackie is utterly desolate and considers suicide and it is several months until with the help of her religious beliefs she is able to begin to restore some order in her life.

Salander and colleagues (1996) commented on their study, "it was obvious that the partners [of the people with brain tumours] were actually less confident and showed more anxiety." (p.988). This study does not make systematic comparisons between patients and relatives, but this point seems pertinent. Nevertheless, for a variety of reasons - most predominantly for the patient's sake - the relatives do keep going through this experience. And for some, the experience is mitigated and a certain purpose may be found through their ability to support the patient. This will be explored in detail in the following chapter.

SUMMARY

Nearly all participants at least initially (and some temporarily) associated the diagnosis of cancer with death. This led to feelings of loss of internal security and change in outlook. Participants experienced a range of emotions which were alluded to in a variety
of ways through the research process, although full expression of emotion was
invariably suppressed. Some emotion had physical manifestation, which might have
long term chronic implications such as insomnia. Most relatives managed the
experience by minimising the threat of the cancer in a variety of ways, although the cost
of this to themselves was often little acknowledged. The nature of the relatives stories
indicated that they faced obstacles to reconstructing a relatively coherent narrative of
their own experiences.
Chapter 6
THE INTERPERSONAL EXPERIENCE
INTRODUCTION

The last chapter explored some of the relatives' more intensely personal feelings and their inner experiences. This chapter which looks at the relatives' interpersonal experiences focuses broadly on two interrelated areas: issues relating to changes in the communication between the relatives and the person with cancer, and on the relatives' ways of caring for the person with cancer. There were again some important similarities between the relatives' interviews. The relatives' need to put the well-being of the person with cancer before their own, and to construct the situation in ways that they believed would make life more comfortable for the patient was present to some degree in nearly all the interviews.

This chapter first briefly addresses the relatives' relationship with the person with cancer in order to provide some illustration of this important influence. Following this other changes in patterns of interaction between the patient and those close to them will be illustrated by the elaboration of the strategies adopted by the close relatives to protect the patient – both physically and emotionally.

Many of the people with cancer involved with this study were relatively well and could 'look after' themselves. Yet, interviews with those close to them revealed the majority of these relatives to be involved in an array of 'caring' activities. Some relatives faced complex practical management of the illness and all experienced some change in their way of life; however there were only a very small minority who expressed any resentment about this. The majority of participants found that providing support for the person with cancer was also rewarding for themselves – 'coping by caring', even though this could become quite stressful, as in, for example, their attempts to nourish the patient. The suppression of the relatives' own emotion and the 'loss of bearings' described in chapter four may also partly explain their need for an outlet in practical activity, a desire to do something. Finally, as there is a predominance of women represented in the study, and women are traditionally understood to be the 'carer', the chapter will briefly discuss the relevance of this.
THE RELATIONSHIP WITH THE PERSON WITH CANCER

One of the fundamental difficulties in writing about the experience of living with someone else's illness is that neither the interviews nor the analysis are intended as an in-depth interpretation of people's lives and relationships. Therefore the personal meaning attached to particular relationships, which are such an important influence on the experience of those who took part in this study, may only be alluded to by the participants. Nevertheless, the 'objectively' different kinds of relationship (for example, wife, sister, daughter) did have a varying impact on this set of relatives.

These differences seemed easier to define after the patient had died. Jackie compared the quality of grief at her mother's death with her feelings at the death of her husband, and was shocked at the difference:

"I was expecting grief to be grief, but it isn't.. it's all in different categories and everything, you know... I mean I lost my mum and I miss her dreadfully, I mean she was my best friend"...

However with her husband:

"have you ever heard the expression about.. you would give your right arm for somebody.. and it's like you've lost a part of you... and I've heard people say that they died of a broken heart... that's true, I'm telling you right now that's absolutely true.”

[Jackie 2 p.8-9]

Both her mother and her husband were a fundamental part of Jackie's life but their respective illnesses and deaths (her mother had chronic health problems) meant that she lost different aspects of her being.

Taylor (1991) argues that we become who we are not by our own achievement or creation but through our exchange with those with whom we are close - they create the essence of our being. He writes:
"Because of this, it would take a great deal of effort, and probably many wrenching break-ups, to prevent our identity being formed by the people we love. Consider what we mean by "identity". It is "who" we are, "where we're coming from." As such it is the background against which our tastes and desires and opinions and aspirations make sense. If some of the things I value most are accessible to me only in relation to the person I love, then she becomes internal to my identity." (Taylor 1991, p.34)

This study is about a threat to these crucial relationships and thus a threat to self identity.

Ivan explained:

"I mean you build your life around a relationship

..................

for 30 years you've known somebody ... it's not a relationship you can give up easy, is it. I mean every morning you're going to wake up thinking.. where do you go from here like."

[Ivan 2 p.12]

Andrea also described this after her husband has died. She also had been explaining how she felt when her mother died and how different it was with her husband:

"different feeling when your husband dies, and it's a thing you can't ever express.. until you go through it, and that's why when people say it... I know how you feel, they don't, unless they've gone through it. You can't explain the feeling, it's just like part of you going really, part of your body is actually gone, because you've been through a lot together, and you've had children, and been through the good times and the bad times.. and .. it's just a feeling you can never ever express, no doubt about it really.."

[Andrea 2 p.28]

Jade described how a different relationship and other life circumstances altered the experience:

"not everyone is like Judith and I. Perhaps if we only had .. me dad, with we've got children, we've got mum, I've got a husband, I've got bills .. you've got other things to occupy .. you know .. everyone says .. how do you cope, but in fact it's easier to cope because your mind is not on one thing, you're not feeling sorry for yourself... and you're not brooding about it.”

[Jade 1 2nd tape p.3]
Some of the participants had complicated relationships with the person with cancer. For example, Alison described her mother from whom she had been separated for a time during her childhood and with whom she was unable to fully resolve her relationship during her illness and death:

“She’s had a very hard and chequered life........
she was a difficult lady and had tremendous problems about guilt, towards me.’
[Alison, 1 p. 2 &3]

Alison probably speaks for many when she comments:

“it’s not just an illness problem, it’s a family problem exacerbated by illness as well”
[Alison 1 p.1]

Jill, as Jack’s long term landlady, found negotiating their rather ill-defined relationship more difficult after his diagnosis with lung cancer. Jill was very emotional about this during the interviews, crying not only about Jack’s illness but also about her husband’s death from cancer 20 years before. Although Jill described Jack as part of the family she had no real ties to him - and yet she had lost touch with members of her own family by supporting him through his illness. Jill made several references to the difficulties of managing this situation:

“I don’t know what I can do, not being that pushy.... all I can do is advise really .. and say to him I don’t think.. I mean if he turns round and says “it’s nothing to do with you” ... it’s nothing to do with me let’s face it.”
[Jill 1 p.12]

Although Doris and Donald were married they did not appear to have a relationship with very close verbal communication: “we never have talked much at all” [Doris 3 p.19]. This did not change when Donald was diagnosed with cancer. Nevertheless Doris wanted to be able to talk about it, whereas Donald was unwilling:
“it’s been almost nil, we just don’t communicate at all, and when I look across there he’s gone asleep....”
[Doris 3 p.17]

Doris believed that this lack of communication contributed to the fact that since the cancer was diagnosed the relationship had deteriorated:

“Oh yes, it’s deteriorated, yes. ...... I said to him how could you give me so much hurt, mentally, I said.. it’s taken over, cancer’s won, it’s beaten you and I said to him... it’s nearly beating me.. because the whole atmosphere at night.. it’s dreadful.”
[Doris 3 p.17]

These more difficult, complex relationships are very likely to be more common in the general population than are represented in this research sample. Those with any difficulties in the relationship are the least likely people to present themselves as being available to take part in a research study which would involve talking about the experience. I suspect that one of the wives who refused to take part in the research may have had rather ambivalent feelings about her husband and this may have made her reluctant to participate. These individuals may also be difficult for health professionals to identify as possibly being in need of support. These relatives may be in a difficult position to ask for or even acknowledge that they might want help. The complexity of relationships which mediate living with cancer in a close relative or friend need to be born in mind when trying to understand this experience.

**LIVING THE PATIENT’S WAY**

Invariably the ways of living with the illness were dictated by the person with cancer. This could create an important change in the balance of a relationship, although at times this change was quite subtle, and the changes would have the greatest impact on those who spent most time with the patient. Thus Ivan bluntly describes the difference between when he had cancer himself and when his wife had it:
“if you got it yourself you can cope with it can’t you, cos you can say I’m gonna do this or I’m gonna do that or..... any bleeding way, but when it’s somebody else, it’s a totally different thing, isn’t it?”

[Ivan 1 p.18]

Ivan found Isabel’s ways of dealing with the illness unpredictable - he was anxious that she may refuse treatment, she is at times very angry, and yet he perceived that he has to support and live with her way of approaching the situation.

Anne could see the hospital where her husband was treated from the window of her flat. Over the seven month period that they were involved with the study Anthony would not allow them to leave the area, not even to visit their son, in case something happened. Anne describes her life:

“We don’t go out travelling, no.. only go out as far as the park and that”

[Anne 2 p.4]

In the interview her husband was quite sarcastic about her desire to go further afield, saying that she can go to the shops if she wants. However, Anne accepted their very altered life style explaining that she copes because her husband “doesn’t harp on about it”:

“like he washes up and all that or he gets the Hoover out, oh yes. He’s not .. an invalid. He doesn’t treat himself as an invalid.”

[Anne 2 p.15 ]

They had been told that Anthony should be cured and yet they continued to live in a kind of siege mentality. Anthony joined in for most of Anne’s two interviews, apparently believing that as he was the one with the cancer then he should be the focus of the discussion. As Klienman comments, writing about people with chronic illness:

“The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long term course of suffering” (Klienman 1988, p.49)
The patients constructed an illness narrative and ways of living with the illness which were right for them and the others in their life frequently also had to live by these. George would not allow Georgina to visit him when he was in hospital - although she was staying only a few streets away - because he did not want her to see him being sick. This increased her own anxiety enormously, so that she almost experienced the same symptoms as her husband:

"Well I used to get choked up......"

However she explains:

"I just thought he was happier the way we done it, well the way he done it really. I mean he wouldn't let me visit"
[Georgina 1 p.7]

Georgina also had to stand by while George cut down his topiary which he had spent years creating, so that the garden would be easier to manage after his death. She hated this:

"and I say George, don't be such a ... get doom laden"
[Georgina 1 p.9]

Andrea found one of the most painful things for her was to help her husband sell his boat which had been his pride and joy. These acts which somehow seemed to represent the early destruction of something which had been the essence of the person were very hard to bear. Jackie, who vowed to maintain her husband's intricate garden as a memorial to him after he died in fact found this a great comfort.

There were practical issues and activities over which the patient held sway, but the relatives were also influenced by the patient's emotional reaction to the illness. Doris mentioned how difficult she found Donald's depression several times:
“Oh dear ... when I wake up in the morning, I think .. oh god, it’s not right ... and I think of ... I think back to the days when I used to wake up in the morning and I thought .. oh life is good. And now no.. I think oh my god, that’s not right... but then I’m sitting in the evening, I can’t look at him, he’s so miserable.. and maybe it is infectious, depression isn’t it?”

[Doris 3 p.4]

On the other hand Doreen and her husband both cited a philosophy of taking a day at a time during the interviews. She found the calm way her husband approached his illness had a very positive effect on the way she herself dealt with it:

“I mean he’s not really allowed it to affect him at all. So I suppose because he’s accepted it like it, then I have.”

[Doreen 3 p.2]

Melvin also cited his wife’s uncomplaining attitude as important in making his life easier:

“Well you know I’ve seen some people.. sort of down at the mouth and all that.. and it makes you feel the same sort of thing, but when they’re not you react accordingly.. and it’s her reaction that’s really made it so easy.”

[Melvin 2 p.8]

And yet the interviews suggest that Monica’s refusal to talk about the more difficult issues surrounding her illness made it hard for Melvin to express his own deep distress. A few participants did voice the feeling that they would like to influence the way that the patient lived with the cancer, although this was also reported to be invariably unsuccessful and frustrating. Andrea is a good example of this:

“I think the only way to get through is to be positive, ........ [but] he actually never thought he would, from the start, never ever thought he’d get through... from the first day he found he had cancer, that was it, and we had to go and make wills out”

[Andrea 2 p.3]
Some participants found it difficult to undertake simple everyday activities without considering their actions in the context of the illness. It was as if nothing else should matter, Elizabeth explained how this made her feel:

"sometimes I'll say to Bernard, "oh, I'm getting the car" and then he's obviously not particularly interested ....... it's then you feel perhaps guilty because you are talking about something so trivial when he's got such an enormous problem um and it is a guilt feeling really when everything in your life is so trivial in comparison with what he is facing".
[Elizabeth 2 p.11]

Bury (1991) describes finding meaning associated with chronic illness. One element of this process he calls 'legitimation' whereby patients attempt to gain some control over their condition by finding explanations and ways of living with their illness that make sense to them.

Klienman (1988), also describes 'legitimising':

"Legitimising the patient's illness experience - authorising that experience, auditing it empathically - is a key task in the care of the chronically ill," (Klienman, 1988, p.17).

Many of the relatives here appear to work hard at legitimising the patient's experience but not their own. A diagnosis of cancer - unlike many other chronic illnesses, invariably is legitimate in the eyes of the individual's social world, and the ways that the patients find to live through this, whether by denial or depression, are difficult to challenge. Thus to a certain extent the patient's ways of living with the illness have to be adjusted to by the relatives.

As discussed in the last chapter, there is however, less evidence of the relatives themselves being able to think about how to make the 'best' of the illness for themselves. Ivan clearly expressed how the person who has the cancer may use their illness to review their life, perhaps to do things that they have always wanted:
"I mean if somebody said to you, you've got a year left... it's likely that you could be selfish...... as it were, to do your own thing."
[Ivan 2 p.8]

PROTECTION STRATEGIES

The diagnosis of a potentially life threatening disease is difficult to talk about. For the relatives who took part in this research it did seem to create a new constraint in the ways in which they interacted with the person with cancer. This seemed to happen even in those who claimed to be sharing the illness closely together.

Communication between patients and their relatives often became structured by the various ways in which the relatives attempted to protect the patient from any additional hurt - either physical or emotional. The perceived threats to the patient's well-being could be both real or imagined. This protection was a strategy which some participants actively pursued. In others it was a subtle change in perspective, an unconsciously-kept vigil. It appeared to manifest in attempts to maintain the fragile emotional balance that could now be upset by any number of what used to be quite ordinary incidents.

Judd (1994) discusses how the 'trauma' of a life threatening illness may pierce our 'psychic protective apparatus' (Judd 1994, p.88). Judd describes Khan's (1986) use of Freud's work which sees the mother's role as a 'protective shield against excessive stimulation for the child' (Judd, 1984, p.88.). Judd elaborates on this using the term 'protective filter' to describe the parents function with a child - this notion being less impenetrable than that of a shield. Judd sees this as something more permeable - the parent may filter what goes through to the child and the child's experiences may be filtered back to the medical team after being processed by the parent. Here, elements of both filtering and shielding were exhibited by the participants' desire to protect their adult relative with cancer from any additional harm.
In this section the dimensions of the broad category of protection are elaborated; filtered communication, shielding, monitoring and encouragement of activities. For the participants in this study, these were not discrete strategies and were sometimes used in tandem. These changes in interaction with the patient did fluctuate in their intensity - the more uncertain the course of the illness, the more likely the relatives were to be protective towards the patient. The patients themselves were also, of course, protective of their family in various ways and this will at times be alluded to.

**Filtered Communication**

The notion of ‘filtering’ and ‘shielding’ described here do appear to be quite similar and it is quite hard to illustrate the difference. However, it has not seemed appropriate to collapse these two ways of communicating together. Filtering would mean less of a block than shielding - perhaps an issue may be discussed with only selected elements being sifted out. Some of the participants were able to talk relatively openly with the person with cancer about the illness and its prognosis. However, even in these circumstances there was sometimes an element of filtering the communication, thus creating changes in the ways participants related to each other. This was more likely to happen with the husband and wife pairs, who having a relatively equal partnership would consider it appropriate to talk together about the cancer. And yet there might still be some areas where the relative wanted to protect the patient from the full extent of the situation.

Stephen and Karen both professed to speaking openly together about Karen’s cancer. However, Stephen was told about the degree of malignancy of his wife’s tumour when she was not with him, and he could not bear to pass this information on to her:

“which is the only thing which I have not mentioned to my wife because we’ve generally got an agreement that we will you know, share everything.”

[Stephen 1 p.11]

Georgina described how she and her husband talked about the illness together and also how this had actually become easier over the five months since his diagnosis:
“Yes, because he’ll tell me everything, he won’t hide... you know, like... before I think sometimes he thinks of your feelings. Well I say to him, it’s not good now, you’ve got to... you’ve got to be open with each other otherwise one of us is going to... you know, you’re going to get a hell of shock. Well not so much now because he says to me “you know there’s no cure”, and we know there’s no cure for lung cancer. But I say well... “you just live in hope... something’s going to happen sometime, isn’t it, we could be one of the lucky ones.”

[Georgina 1 p.11]

This couple were able to talk about the fact George would die in the abstract, and yet this was obviously difficult to really accept. They talked about the cancer but the real impact of this was in many ways filtered out. This is perhaps similar to the ‘shadow reality’ as described by Rosenblatt (1984) in chapter two (Marriage and close relationships). And as I commented in my field notes:

“she was a woman who was overfull really with emotion and grief and sadness about what was going on”
[Georgina 1 p.13 field notes]

Jackie also felt she had close communication with her husband Jonathan. She felt that they were being open about the disease and prognosis and she also, like Georgina, felt that this was getting easier with time:

“And right from the beginning from the word go we.. actually sat down and we talked about this and we talked about that... Jonathan wanted me to think about the future, obviously I didn’t, and he said “I want you to get married again...” and I said “you’re joking not after two times”. I said no, I said.. it’s enough that I’ve known you, and I won’t be on my own. I’m more stable now than what I was at the beginning of finding out”
[Jackie 1 p.9]

However as Jonathan’s physical condition deteriorated it was not possible for this communication to continue and the balance of the relationship changed. Jackie felt very isolated and whilst respecting what Jonathan wanted, she felt had to make all the
decisions on her own. She also felt that despite their preparatory conversations she had not anticipated the enormity of her grief after Jonathan died.

"I was prepared for the practical bits of what would happen, I knew exactly what I would be doing.. because Jonathan wanted me to do it, you see, but for the emotional bit, no I weren’t prepared, I wasn’t.. not at all.. not at all."
[Jackie 2 p.19]

Where the relationship is between the parent who has cancer and their child - however old, then it may be that the parent had never talked very openly to their offspring about details of their health, either physical or emotional, thus making difficult issues hard to acknowledge. Andrea and Stephen both talked in their interviews about filtering the news before telling their children to protect them from the most distressing details.

**Shielding**

Shielding or buffering the patient from what was perceived as any additional hurt was referred to by several of the participants. This involved three broad areas; first attempting to shield the patient from distressing or difficult information. Secondly, attempting to shield the patient from being aware of the extent of the relative’s distress caused by the illness. Thirdly, by not talking about and acknowledging the illness some believed this would reduce its impact.

By not referring to difficult issues surrounding the cancer, shielding may also afford those close to the patient some protection from facing its potential consequences. Shielding the patient of course is a further way in which barriers to communication are created once the cancer has been diagnosed.

(i) from difficult information

To take shielding to its limit the family may want to prevent the patient from knowing their diagnosis at all. This did not occur in the present study (indeed a criteria for patient entry into the study was that the patient had been informed of their diagnosis). However
Betty did manage to obtain information about the progression of her father’s illness from his GP without telling her father about it, she explained:

“And we asked the doctors not to tell him, because we thought... it’s a bit traumatic when you’re eighty... to have to live with knowing you could die.”

[Betty 1.p.2.]

A few of the relatives did try to shield the patient from knowledge that their outlook might be more uncertain than they hoped. The adult daughters exhibited this form of shielding most clearly. Judith and Jade were very protective of their father, despite still feeling in awe of him in many respects. As well as the many practical difficulties created encountered in trying to arrange to interview him, I am sure that one of the key reasons that I did not manage to talk to Julian was that the daughters were being rather obstructive - perhaps because they were concerned about what we might talk about. The daughters wanted to be able to manage how information was given to their father, as Jade explains when she was told by the doctor that his lung cancer was inoperable:

“I warned them, I said, “look, he is very deaf”.... I knew they couldn’t do it in a ward ‘cos everyone else would hear, you know... and I said, “he is very deaf, so .... could you make arrangements to tell him when he’s on his own or whatever”.. but they didn’t really pay a lot of attention to that.”

[Jade 1 p.9]

In this instance the daughter was also trying to (unsuccessfully) shield her father from mismanagement of the communication of his diagnosis. Several relatives talked in the interviews about wanting to ask questions of the health professionals. However they felt unable to do so in the presence of the patient because they did not want the patient to hear the information that they were seeking (see Blocked by the person with cancer in chapter seven).

(ii) from emotion

One of the most common and apparently strongly-held beliefs expressed in this study was the participants’ feeling that they should suppress their own distress about the
patients’ illness in order not to create further anxiety for the patient. This is also one of the important explanatory factors behind relatives’ lack of acknowledgement by health professionals (see Invisible relatives, chapter seven).

James (1989), (see Caring in chapter two) describes emotional labour as more than a ‘formulaic response’ to a situation involving the feelings of others. Hochschild (1983), writing earlier than James and actually referring to emotional labour as sold for a wage (by air stewardesses) nevertheless, does describe elements of what these relatives achieve. Hochschild defines emotional labour as: ‘the management of feeling to create a publicly observable facial and bodily display’, which would produce in others a sense of being cared for in safe place. In this study, something similar is displayed by the relative’s of people with cancer. George and Georgina professed to talk about the illness – the closest conversations appeared filtered, but certain issues were shielded by Georgina. In Georgina’s second interview she had explained that she knew George worried about her. Therefore Georgina aimed to show him that she could manage and indeed she would be able to live without him if he died:

“I try to hold it in. And he’s ... I suppose what I try to do a lot is to make him feel that I can manage, cos that’s what he worries about.”
[Georgina 2 p.6 ]

By her third interview Georgina said that she felt calmer about her husband’s illness. However, although Georgina did not want to keep things from her husband, even after living with the illness for over a year she still would not risk upsetting him by revealing her own distress:

“I suppose now and again I have a cry ..but I mean I’m on me own then. I don’t .. I suppose I don’t hide things from him, but I wouldn’t let him see me upset cos it would upset him.”
[Georgina 3 p.19]

Andrea expressed this very clearly when she describes how the only time she feels able to cry is when she is taking the dogs out for a walk. Mary also knew it would hurt her
sister’s pride if she saw Mary crying about her illness and its symptoms. She described how she rushed to the toilet when she felt her eyes filling up with tears:

“Well cos it will make her worse. And then she’ll think .. oh she’s feeling sorry for me.”
[Mary 2 p.6]

Samantha’s third interview was quite different from the first two. This may be because she knew me better but also because her husband was not present. She admitted that she worries in her ‘heart’:

“No, I don’t worry about him. I do in my heart like, but I don’t let him see I’m worried .. because I ... he’ll say.. “I don’t know what you’re worrying about, I’m alright, I’m alright”.
[Samantha 3 p.3]

One of the changes in the every day social interactions of the participants was that they felt that they could no longer get angry or have a row with the person with cancer. Terence had had a life of many arguments with his wife, but now he said:

“I just keep me mouth shut and that’s it”
[Terence 1 p. 13]

Ivan made a secret visit to his GP, not to find out about his wife’s prognosis, but to discuss how to avoid showing his difficulty in coping with her hair loss. Unfortunately, he did not find this helpful.

The participants made light of or did not mention their own physical disturbance. Jill described a very restless wakeful night which she felt she could not tell Jack about because it would make him feel “bad”:

“No, I didn’t say .. it’s not fair is it, cos if he thinks I’m worried, really I think he’d feel more bad about it”
[Jill 2 p.25]
Elizabeth explained how as well as not wanting to show her brother her distress, she also felt she should protect their elderly mother who lived with them from emotional upset. She described how it is hard to talk openly to close family about sensitive issues.

"when you are close to people you tend not to want to worry or upset them, there is this barrier, between close relationships"
[Elizabeth 2 p.12]

This sounds very familiar and of course is not exclusive to cancer as Rose illustrates when she described one of her reactions to her father’s death from heart disease:

"Well, it’s always so difficult, one is trying to suppress one’s own grief a bit in order to help her [her mother] out."
[Rose 1 p.2]

Rarely, or only under very controlled circumstances, were the relatives able to fully express how they felt. They might be tearful at times but the opportunity to really talk about it, particularly to those who were closest to them were rare. Thus to some degree they were all performing what Hochschild (1983) described as ‘deep acting’ (see Approaching emotions, chapter five).

Finally although the focus here is on the way the relatives were attempting to shield the patient from emotional distress, these strategies obviously did have their own impact on the patient themselves. Mary’s sister complained of feeling “suffocated” by the way Mary manoeuvred around her need for independence despite her illness and increasing weakness. Georgina describes her husband’s response:

"I mean he laughs, he said “you’d think I was a ... mustn’t touch ... you treat me like a bit of rare”"
[Georgina 2 p.15]

Jackie describes Jonathan’s reaction as she excluded him from a conversation with a distressed neighbour at the door:
"what's going on?" he said .. "I'm still the superintendent here", he said. And I realised after, I said, well I didn't think you'd want to be bothered, I thought you'd be upset, you know, so I did try to protect him from the sort of ... but you see .. the way he reacted.. he's still the same.. he's not dead and buried yet. You see, he's still able to want to be involved and that, and we shouldn't put him away, to try and protect him."

[Jackie 1 p.19]

Perhaps some of these strategies contribute to 'social death', whereby, 'people cease to exist socially before they are biologically dead' (Small 1997). Here, death may be seen as a process in which the dying are treated by others in ways that are different, and possibly less inclusive, from when they were well.

(iii) by not talking about it

Some families, although declaring a close relationship, seemed to have only a very minimal acknowledgement and communication about the cancer. They may have had an open or an implicit agreement not to talk about the cancer, but they each had their own understanding of and feelings about this 'agreement'. The couple who most exemplified this were Melvin and his wife. He explained this at his first interview:

"We decided ... the wife and I .. well we won't tell anybody.. we'll just hope that that's the end of it. Why put them in that position unnecessarily."

[Melvin 1 p.3]

They did not tell the diagnosis to their 36 year old daughter who lived with them and shared in her mother's care. By the second interview Melvin did seem somewhat calmer. However, when I asked him if he and his wife ever talked about it he replied:

"No, we don't talk about it at all, because it's either here or there, you know what I mean"

[Melvin 2 p.4]

I was very concerned that the research process itself may be challenging the way in which they had decided to deal with the illness and was rather relieved when he said that they did not want to continue to a further interview:
“Well we’ve done what we’ve .. put here and I think that’s quite sufficient, I wouldn’t want to go any further than that”

[Melvin 2 p.13]

It is difficult to make comment on how people communicate on the basis of an interview transcript. One couple who were only interviewed once gave quite conflicting stories as illustrated by the field notes:

“but the thing she (the patient) really emphasised was that her husband never ever mentioned the cancer at all, and never spoke about it............which is quite interesting, because he is the person... every time I rang up he kept on shouting out “here Teresa, it’s that woman about the cancer on the phone”

[Terence 1 p.27]

Terence also had little difficulty in talking about the cancer and its emotional consequences during the taped interview.

Jane’s father did not acknowledge his diagnosis of lung cancer during his own research interview, and although Jane provided him with enormous support - seeing him every day, she also found it difficult to talk to him about the cancer. Her father did become very depressed (which may well have been as a reaction to not expressing his fears) and was admitted to psychiatric hospital:

“he just didn’t know what to do with himself. And he said he felt suicidal”

[Jane 2 p.3]

By the third interview although her father was still coming round every day, Jane comments that, “it’s much better”. The anxiety only became acute as he approached his hospital appointments. Indeed, his diabetes worried Jane far more than the cancer.

**Monitoring**

Surveillance of the patient’s environment for anything which might disturb their well-being was something that several of the participants talked about doing in varying
degrees. The relatives also monitored the patient for any subtle change in their health. Constantly being on the alert for signs of anything untoward might be one of the ways of allowing the relatives to feel more in control of the situation. This undoubtedly happens with many other illnesses, however the unpredictable nature of cancer and that a change in condition might be life threatening may have accentuated this.

Relatives tried to monitor the patients’ well-being in several ways, for example by observing how much the patients ate or were able to do. Stephen inquired what might be the possible signs of cancer progression and described himself as:

“trying to keep a quiet eye on things without saying anything”
[Stephen 1 p.11]

Jane had a constant nagging worry about her father’s well-being. She was concerned that he got home safely everyday and this changed the ways she interacted with him:

“I do mostly phone him when I get in, just to make sure that he is OK.”
[Jane 3 p.5]

Geoffrey was very anxious about his wife’s recovery and this was exacerbated by his disability. Using language which expressed what he would like to do, but because of his visual impairment he could only do through his son, he said:

“I keep a beady eye on her, every time my family arrive I say how is mum looking, do you think?”
[Geoffrey 3 p.18]

Most of the monitoring activity was rather covert, the relatives not necessarily wanting the patient to know that they were doing it. The relatives observed the person with cancer to make sure that they were not overdoing it or taking on more that the relative felt that the patient could cope with. Mary describes going out shopping with her sister and attempting to manage the situation without being too obvious:
“I’ll say... let’s have a cup of tea and piss off home love... I’ve had enough... cos I know... I can tell by her [Mavis’s] face that she’s had enough, you see.”
[Mary 2 p.26]

Elizabeth explained how she had become “super conscious” about cancer and the media. Many of the participants commented upon the impact of the unexpected intrusion of drama about cancer or current affairs, for example the use of mortality statistics to illustrate a news item on the morning radio. Elizabeth clearly explained how she monitored for this:

“I tend to scan the Evening Standard and look for all the things that might be on [about cancer] and try and watch the other side.”
[Elizabeth 2 p.5]

Elizabeth described how she tried to protect her brother from exposure to issues about cancer:

“You want to protect people I think yes and maybe he doesn’t feel like that at all I don’t know
...
You’re sort of thinking ahead, trying to think ahead all the time um he’s not so conscious at all”
[Elizabeth 2 p.6]

Like many of the relatives Elizabeth seemed to feel that she had little control over what was happening but this process of monitoring seemed to be one way of reducing some of the uncertainties.

*Encouragement of activities*

Several of the participants in the study, particularly the women, felt that they should attempt to protect the patient from being ‘down’ and introspective and thus, in their perception, more vulnerable to the cancer. These relatives believed that they could do this by encouraging the patient to get out and think about other things - in some ways they were hoping to insulate the patient from their own negative thoughts. Many
relatives seemed to think that having a ‘positive’ frame of mind was important for recovery. Doris explained this in her first interview:

“I wanted him to find something that was good, a hobby, so that the atmosphere would be better. I said you know if you have a hobby and you throw yourself into it you forget a lot”. And I said “it’s very bad, it’s very bad for you physically and mentally, for this to go on. So it just used to make me feel very, very, miserable”.

[Doris 2 p.2]

Rose also felt this about her mother who she thought looked like a “victim from Belsen”, when Rose arrived home.

“I’ve forced her into eating and going out and meeting people again............. she must make the effort to see people”

[Rose 1 p.6]

Jill held a deeply felt conviction that Jack should be getting out and doing more.

“quite honestly, apart from him being ill, he doesn’t help himself, he’ll sit and think about it.”

“But I just wished he would find an interest so it gets him out more.”

[Jill 1 p.8]

In her second interview, Jill described how she attempted to facilitate this and how she wished that the hospital had given Jack more information about what he could and could not do. These attempts at encouraging the patient’s activities again seemed to be a further way of trying to control the situation. Such attempts at protecting the patient were also a way of trying to prevent the cancer from engulfing their whole lives - for both the patient and their relatives. Jane gave an example of where attempts to distract her father had actually worked out:

“But as I say he’s alright, he’s a lot better, since he got that allotment”

[Jane 3 p.5]
Almost all the participants expressed some form of protective behaviour or attitude during the interviews - with the usual exception of Robert. The majority of the adult offspring who took part in the study did take on a protective role. For some the cancer diagnosis might have brought about a change from being protected to becoming protector, for others such as Betty they may already have altered roles as a parent became more elderly. Two wives who had themselves either been ill (Doreen) or were still ill (Julia) appeared to be least protecting.

Protection of the person with cancer was also a form of self-protection. If the patient was less distressed about the cancer then this may make things less emotionally painful for the relative as well. The attempts at protection could be seen as a way of denying the uncertainties and potential gravity of the situation. There is also evidence in both the relative and the patient interviews of the patient's attempts to protect their family's feelings. For example, Karen wishes that she could go to the hospital without Stephen because she wants to ask questions to which she believes Stephen might find the answers painful, or Nora making great efforts to protect Geoffrey from becoming unbalanced by her illness.

The analysis of these interviews is written from the relatives point of view. However the difficulties in communication will also have important implications for the person with cancer. Moynihan and colleagues (1988) who looked at the impact of testicular cancer on patients and those close to them found that the patients who took part in their study appeared to have appreciated the presentation of a 'brave face' by their relatives. Wortman and Dunkle-Shetter (1979) on the other hand found that the belief by those close to the patient in the need to be encouraging and optimistic led to potentially awkward and superficial interactions which were less likely to fulfil the patient's need for support.

Between the person with cancer and those close to them there may thus be a separateness, a distance in their relationship which had not been there before, potentially making a very lonely and anxious time even more difficult.
RELATIVES AS CARERS

Implicit in this chapter so far is that one of the principle changes for these relatives was the way in which they communicated with the person with cancer. Unlike many studies about the families of people with cancer, this did not set out to be a study about caring. It is about the experience of living with a diagnosis of cancer in someone who is a close relative or friend. Nevertheless, caring is obviously an element of this experience and many of these alterations in the relationship between the patient and their family and the changes in day to day living may be defined as care. Several of the patients in the study were relatively well, but they still might be perceived as having additional emotional needs to be cared for. For example, the protection strategies may be seen as a way of caring for the patient. Some of the patients who were involved in the study did require quite significant amounts of physical, practical caring by their relatives. For example, Jade and Judith had to bed bath their father and Jill looked after Jack when was desperately sick before he was eventually taken in to the local hospice. Jackie gave up her job to care for Jonathan, enabling him to die at home.

There are many ways of defining care. Jackie describes her care for husband:

"just love and attention and care and feed him and everything... that was it. that was all that he was given, and that was what I could give him. There was nothing else that he needed actually."

[Jackie 2 p.27]

Practical issues

Few relatives interviewed really complained about the additional practical support necessitated by the patients' illness. But providing practical support for the patient was most difficult when there were other demands on the relatives' time.

For a couple of the participants their employers were particularly unhelpful. When Elizabeth wanted to take some time off work, her boss's unsympathetic response was to
question why she would want to risk losing her job now for a brother who would be
death in a few months. Elizabeth felt that there should be more help:

“And I feel very strongly now that there should be more support, um albeit
that I hate legislation by the government.........................

There must at least be some allowance even if it was half a day a week that
to take the pressure off doing the shopping, doing the washing, you know
tidying the house. Um but there is nothing for people in this situation.”
[Elizabeth 1 p.6 ]

Ivan had little support from his supervisor at work to allow him to be at home when his
wife had her treatment:

“I had a day turn and I had a lot of flak locally, from the supervisor, that I
was dodging the column anyway, and in the end they wrote me a letter
saying... which was the first priority in life, my job or me family?”
[Ivan 1 p. 16]

Certainly, financial resources could make a difference. Stephen could afford to say that
he would take six moths unpaid leave and be confident of his job security. However, his
daughter found it a strain. Louise took some days off work to be with her mother when
she was recovering from surgery but describes it being difficult when she heard “a very
feeble voice coming from downstairs” wanting some breakfast:

“because I wanted to lie in. I was genuinely tired... maybe reaction to
everything that happened... in the last few weeks...and it made it difficult to
actually wake up and go downstairs.”
[Louise 1 p 10]

Jade and Judith both had families with quite significant problems of their own,
nevertheless they gave an enormous amount of practical support to both their parents.
They would go with their father to hospital appointments and ensure that the GP was
aware of his problems. Sometimes they would be round at their parents house five times
a day:
“people say well you’ve only got to get a prescription ... but you go back cos in between you’ve got to empty a commode, you’ve got to pick your children up from school, you’ve got to get your house work done... so you can’t hang around waiting for a prescription, you’re backwards and forwards”.

[Jade 1 p.16]

Jane also saw her father to support him everyday. However, she found that over time her responsibility decreased and became easier. Her last interview was almost exactly three years after her first and she comments:

“Yes, definitely easier for me cos I’ve got different.. I mean I’ve got different responsibilities. I mean I’m not just here for him and he knows that.. and that’s helped him, because he knows I can’t be here. He can’t just phone me up and.. sort of be down here and all that, Cos I’m just not here

No, I’d definitely say there’s an improvement from the last time”

[Jane 3 pp.10 and 11]

On the other hand, Doris, by her third interview, felt that her life was being overwhelmed by the essential practicalities of living with her husband’s cancer. She had few other major responsibilities but felt that this really impinged on what she herself wanted for her life:

“all I feel I’m fit for is mucky jobs and all the mundane things. I feel that I want a bit of something else.”

H P: Do you feel your time is filled up with that?

“Oh yes I begrudge it, I get cross.. I’m angry ... because I want time to do what I want to do, so that’s what I get angry about, I think well this is my retirement ... and I’m having no time on my own.”

[Doris 3 p.8]

Doris and Elizabeth both spoke about their resentment of the changes in their lives caused by the illness - if not of the patient themself. This made them both feel uncomfortable. Jill on the other hand, despite their ill-defined relationship, did not seem to question the high level of care she gave to Jack before he died. This was not easy
because Jack's distress made him quite abusive to her and the health care professionals remained unaware of his plight. She described how she was unable to get him back upstairs shortly before he was admitted to the hospice to die:

"well I felt useless because I'm trying to help him and I just couldn't. I didn't have the strength, he was too much of a dead weight.. and he couldn't push himself...

I brought the mattress down for him and I slept on the settee for a couple of days, then one day he was really, really bad"

[Jill 3 p.2]

Jackie, unable to communicate with Jonathon as she used to, felt isolated by the experience of caring for her dying husband:

"when one is in need and the other one is the carer.. that carer has to make all the decisions .. what she or he is going to do for that loved one, and sometimes.. when it gets to a point like, when he became very ill.. like the sponging down and everything, you see, I just automatically did that, and I thought am I doing the right thing should I go?"

[Jackie 2 p.28]

The physical aspects of care became more difficult when other areas of life were unsupportive or challenging. This appeared to become harder when the patient is very sick. Furthermore there appeared to be only minimal professional support for these relatives (see next chapter).

In the studies looking at the burden of care giving with cancer (Oberst et al. 1989; Carey et al. 1991; McCorkle et al. 1993), it was in fact the emotional support which appeared to require the most effort for the relatives. Only 7% of the bereaved family surveyed in Addington-Hall and colleagues (1995) study found caring for their dying relative burdensome whilst 53% found it rewarding. Despite the difficulties that some of these relatives experienced, this research would seem to broadly corroborate these statistics and furthermore gives some detail to help understand the experiences behind them.
What follows will illustrate how important providing care can be in sustaining those close to the patient.

Need to care - 'coping by caring'

So far this analysis has indicated that it is difficult for those close to someone diagnosed with cancer to find any compensation for themselves in the experience. However, as Klienman (1988) writing about the personal and social meanings of illness, comments, “For family members and practitioners, moral insight can emerge from the felt experience of sympathy and empathy” (p.55). Although caring for a sick relative is not necessarily something that one would hope to experience, some participants did at least feel some satisfaction and believed that they gained something for themselves from this experience. Georgina said at her first interview:

“I think I get.. not pleasure, you can’t say that.. I feel I’m doing something if I’m doing it for him... you know I can do it... so I’d rather not have people do it for him, because I can do it.”
[Georgina I p.12]

Stephen described his urgent unquestioned need to care when he talks about taking unpaid leave from work after hearing his wife’s diagnosis:

“and somebody else said “you know it’s very good of you to give up work rather than trying to bury yourself in the work”. Um and it was no more like that than flying to the moon er I thought about it over that night and there was no way I could vaguely think about going to work.”
[Stephen 1 p.23]

Although he was retired, Melvin expressed similar sentiments:

“there’s no two ways.. I’d have taken it like if I’d been anywhere else I’d have had time off.. because she wouldn’t have been on her own.. no, that’s a certainty”
[Melvin 1 p.10]
These are similar expressions to the example found by Rose and colleagues (1997) as illustrated in chapter two, where a husband is described as seeing his caring as 'the naturally and unquestionably right course of action' (p.131). Caring however, is sometimes elucidated in terms of its burden because it may involve enormous additional practical and emotional activity. Jackie feels strongly that caring for her husband was not a burden and would not want anybody else to do it:

"what kind of burden is it? If it is classed as a burden.. I don’t class him as a burden, not at all. I don’t class it as a duty, not at all. I do it because I love him, I love him."

[Jackie 1 p.15]

For some of the participants in this study their wish to care for the person with cancer became integral to their self-identity. The long-standing relationship with the patient may mean that the relative may not comprehend any other option but to care. To others in their social world the person who is caring may appear unselfish and ‘heroic’, nevertheless the relative may be doing the only thing that feels ‘right’ order to live through the situation. Benner and Wrubel (1989) have developed this theme:

"caring allows the person to focus on the event or the one cared for rather than on personal threat. For example, people may be quite heroic in caring for a loved one with a serious illness. To someone not in the situation, this kind of caring often appears courageous. The caregiver, however, does not feel “courageous” because the person is doing the only thing that he or she can do.”

(Benner and Wrubel, 1989, p.3-4).

Jackie explained how very hard it was not to be able to do anything to alleviate the situation, when her care could not alleviate it (and if anything it aggravated it):

“it’s the watching, it tears you apart inside, because you can only do a certain amount for him, and sometimes I know I get on his nerves, I say, can I get you a drink ... can I get you this, shall I do this for you, shall I do that for you.. what if you, had this, what if you have that, and I know sometimes it does get on his nerves.... but it’s my way of trying to do something for him, and when I see him sitting there... really .. surviving as it were, and struggling.”
Melvin appeared to see this in a similar way. He made two comments within a short space of time:

"just be thankful.. anything you could do, you could do it.. there's nothing.. no hardship, no problem."
[Melvin 1 p.5]

"Well, just watching her... yes. Yes, I think because there's nothing you can do... you see her.. you feel helpless in that sense"
[Melvin 1 p.5]

Andrea who organised others to run her business so that she could be with her husband all the time was able to recognise what support she gave sometimes without 'doing' anything;

"He gets very miserable and very lonely .. and they want someone there, just to be there, not necessarily to even talk, but just to be there"
[Andrea1 p.22]

Elizabeth expressed many mixed emotions about her brother's illness. In the end one of her most difficult problems was that despite trying hard, she never really got any satisfaction from being able to make things better. She explained in tears:

"You feel you've done everything that you can and then you're just shut off from it when you feel you want to be there. And you want to say something, [but] you're not being given the opportunity to sort of say the right words..... I think that's one of the hardest things is when you feel you could be there for somebody they put up a barrier against you..."
[Elizabeth 2 p.8 - 9]

Samantha who had without question offered her husband enormous support, could not help him for a while after her own diagnosis with a brain tumour, this was a physical restriction which went against her natural inclination:
“been difficult for me because where I was helping him, it’s threw me all back, I can’t help him at all now”
[Samantha 2 p.9]

This need to care was not always appreciated by the patient, even when it was welcomed most of the time. Georgina comments on this:

“Yes, well he says. “you’re going to smother me”. Well I think sometimes I do
[Georgina 2 p.15]

Nevertheless, rather than ‘coping by caring’ it is perhaps more common to talk about the relative’s ‘coping with caring’, as Anderson (1988) elucidates in describing the relative’s quality of life after stroke (p.22). Even in Anderson’s study however, the majority of supporters said that they accepted or did not mind the practical help that they gave. These carers were often more concerned about the patient’s mental state and restrictions of their social activities (Anderson and Bury 1988).

The satisfaction of caring, although expressed by many, was not universal in this study and the difficulties encountered by some people in providing practical support must not be minimised. The relationship between the patient and the carer is obviously crucial to how the giving of care might be experienced. Alison felt quite differently about caring for her mother:

“There were too many physical/emotional problems on her side, my side.. between us, I could not do .. I could not give her the care that I know was needed, especially as the illness was going on and there were drugs involved and so on. It frightened me almost to death .. it really did, and it was something I just couldn’t do.”
[Alison, 1, p.7]

Rose although outwardly appearing to offer her mother an enormous amount of support actually felt that she was very unsuited to the task:
"I’m so impatient, I’m not the right person to try and deal with a situation which really needs a lot of patience.. I haven’t got it.."
[Rose 1 p.14]

Julia was so disabled herself that she believed that she was able to offer little support to her husband:

“not much you can do about it”
[Julia 1 p.4]

However her daughter Judith whilst acknowledging the practical limitations of the situation, felt that her father’s illness had actually given her mother some motivation:

“to be quite honest she’s better now than she was.......... Because she’s got to look after him, yes, yes, she’s much better”
[Judith 1 p.5]

Feeding
One thread which ran through many of the interviews was a concern about what the person with cancer was eating. Loss of appetite is an early symptom of many cancers, particularly lung and bowel cancer. Putting on weight or losing weight were seen by many as an indicator of the activity of the cancer. An old colleague frequently quoted from a now unrecollectable source that, ‘appetite is the barometer of the patient’s well-being’. It seems many of the relatives who took part in this study would concur with this sentiment:

“And we do we take one day at a time, so if it’s a good day, and I say a pretty reasonable day, then he can eat a little bit more than what he did do”
[Jackie 1 p.7]

The relatives often took it as their responsibility to nourish the person with cancer and encourage them to eat. This could thus make the relative feel responsible for the patient’s health and their struggle against the disease. When the effects of the cancer and its treatment meant that the patient did not feel like eating, this could become very stressful for all involved.
Georgina explained how before George was diagnosed he was only eating a ‘weenie little meal’ [Georgina 1 p.2]. Georgina clearly associated getting George to eat with restoring his health. At the end of the second interview transcript, three pages are filled with her efforts to entice him to eat. Georgina had occasional successes but also much failure. She did not talk about it being an effect of the cancer and rather she blamed herself or the ingredients for the fact that: the potatoes were ‘earthy’, the chicken ‘as tough as old boots’, the braising steak a ‘bit ropy’, sausages ‘horrible’, soup sets George ‘coughing’, the lamb has ‘been stringy’, the boiled rice ‘congeals’ and the macaroni was ‘vile’ [Georgina 2, p.20-22.

It was obviously disappointing when the person with cancer did not eat the meals created by all these special efforts. Norman described one such incident:

“I mean I’ll never forget... what I did get for you one morning, or one day rather special ... and I thought well I’m not gonna tell her, I’ll just give it to her, I got to the door........

... [his wife said] ‘take it away, take it away....’

I was so choked”
[Norman 1 p.1 - tape one side 2]

Arthur had been strong and very physically fit before his cancer very quickly reduced him to becoming almost chair bound. Andrea’s innate belief was that she had to get him through all the treatment and its consequences to get him well again:

“Wouldn’t eat, wouldn’t drink.....

So I was making up huge saucepans of minestrone ... because I felt if he couldn’t eat anything solid at least if he had some sort of fluid.....

I think that the mental problems he was going through were worse than anything else... cos he could see himself loosing weight as well”
[Andrea 1 p. 8-9 ]
Rose prided herself on getting her mother to eat better. This was very much part of her rigorous plan to improve her general well-being:

"I've forced her into eating and going out and meeting people again"
[Rose 1 p.6]

Melvin disapproved at the food served to his wife in hospital. As he rightly commented:

"you feel better if you eat well"
[Melvin 1 p.2]

Eating is associated with health and normal human day to day social interaction. Feeding the patient and getting them to eat was also for some relatives an important mechanism for maintaining a degree of balance in their lives. It also allowed them to at least try to exert some influence over the patient’s welfare, and potentially make a contribution to improving the patient’s well-being.

As Farb and Armelagos (1980) begin their chapter on ‘meal as metaphor’:

‘Because of values that go far beyond filling the stomach, eating becomes associated, if only at an unconscious level, with deep-rooted sentiments and assumptions about oneself and the world one lives in’ (Farb and Armelagos 1980, p. 115).

Cleaning
Cleaning and other household activities may also be a way of creating some order in the external, if not the internal, world and can be an activity which provides a means of getting through a stressful time - although may not be actually directly associated with caring for the person with cancer. Debra needed to be doing something when Stephen was in theatre having his operation. She could not sit still and allow herself to reflect on what was happening:

"Stephen was gonna be operated on the Friday morning ... so I pulled my house apart Friday morning, I cleaned every nook and cranny possible......."
Doreen recounted a similar urge:

"I think probably the worst day was the day that he actually had the operation, but even then I really wasn't on my own for too long. I decided that day I would perhaps ... spring clean or do something, to keep me mind occupied."

And Mary waiting at home to hear news of her sisters clinic visit:

"so I got a big bucket of Ariel water and a broom and scrubbed the hallway from top to bottom, cos I didn't want to ring her, cos I knew she had bad news because she didn’t ring me"

Cleaning seems to be a common but little explored way of coping with anxiety. When at a workshop on stress attended mainly by Macmillan nurses, participants were asked about their coping strategies I was surprised at how many reported cleaning the floor or cleaning the windows. My father talks of how he played and played the piano the night my daughter (having been given a 50/50 chance of survival) was born. It seems that repetitive activity can be distracting.

On the other hand, it is possible to get too overwhelmed by the situation to manage the cleaning. This may not matter to some, but it could be a very visual sign of not being in control. Jade explained how it felt to her:

"So I knew, as soon as they said it was [the name of the hospital] I knew it was cancer. Then I cracked up, mainly because of coping with what happened.. well looking after my husband with his grief, which he found hard to control... looking after the children and the house.. started getting... a silly thing started getting dirty. I looked and thought.. it’s filthy... it’s really.. filthy, cos I was always house proud. As you can see I’m not now, and it really got to me... not that me dad had cancer or that my mum had all these problems... my husband's dad hung himself... his mum had died... nothing like that.. I thought.. I can’t wash my paint work down (laughing).. and he
[Jade's husband] looked at me as if I was mad... but that must have been the breaking point. you know... and I said I can't cope with the housework... now I've coped with everything else, why would housework... you know, it's not the end of the world... but that's what worried me... not being able to cope with the housework.”

Williams (1993) comments:

“Dirty things piling up are a sign of individual loss of control and social disorder and cleaning is part of a wider attempt to construct order within the life-world.” (Williams 1993 p.98)

A loss of command over one’s immediate environment can make everything feel unmanageable. Walker, in his novel about his bereavement, explains how determined he was to maintain this element of order:

“Within a few days, I became obsessional about housework. It was I suppose, a kind of gesture of defiance, a gobbing in the face of my widowerhood”. (Walker, 1992 p.30)

Thus practical activity as well as giving some personal rewards in relieving the sick person’s distress may also have the benefits of ‘doing’ something, rather than at times the almost unbearable ‘watching and waiting’ for events to unfold.

**Gender and caring**

The majority of the relative participants in this study were woman (19:7), reflecting the feminist contention that the majority of people who define themselves as carers are women (Twigg 1992; Henwood 1998). And, even if the women here did not necessarily define themselves as carers, they appeared more involved than their male relatives who took part in the study less frequently.

Many of the women in the study reflected the view that women cared, were strong, and could cope with difficult situations:
“the woman is the one, isn’t she dear, that organises and does all sorts of things”
[Doris 2 p.3]

Whereas men were seen as weaker, less able to deal with their own illness or that of others:

“They say that with men though, don’t they. They’re dying when they’ve got a cold, or they’ve got a headache or something terrible”
[Jill 1 p.12]

The women tended to perceive themselves as the organisers and some of the men also viewed women in this role. As Melvin explains:

“a woman is.. you’re just that bit extra, cos they do all the chores in any case, which we don’t do you see, so obviously it comes that little bit harder, for us, our capabilities”
[Melvin 1 p.6]

Nonetheless, although the women may inherently believe that this was their role they did not necessarily feel fulfilled by it. Doris was resentful about her husband’s illness, but it was her caring role that particularly irked her:

“I do resent, I think most women resent that they, oh they’ve got shackles. My daughter thinks she’s got shackles with the children.”
[Doris 2 p.8]

Louise believed the responsibility to look after her father if anything happened to her mother was going to be hers;

“boy’s don’t do that sort of thing, you know .... he’ll be going off to university ... and so there’s just me”
[Louise 1 p.14]
Robert on the other hand did not express any notion of needing to care for his mother or of it being a duty or a burden. He felt very sorry about his mother's problems but he did not think that there was much that he himself could do about;

"there was not a lot that I could actually do in that situation,"
[Robert 1 p.4]

However it was less acceptable for the daughters to take on a physical caring role with their fathers. Betty felt she was fortunate because her husband was able and willing to undress and shower her father because in the father/daughter role she found this embarrassing. Jade and Judith had great difficulties:

"I think that's what upsets you more than anything, to see him let you do that. I mean he would never let anybody do anything like that before, like if he had to use a commode"
[Judith 1 p.4]

It is perhaps not surprising that there was a predominance of women in the sample but it was not just gender which determined responsibilities, for example, why was it one sister or daughter rather than others who was the key person for the patient? Jade and Judith came from a very large family with several other sisters. However Jade and Judith had an extremely close and supportive relationship with each other:

"If me sister's there then we can sort it out between us"
[Judith 1 p.9]

Betty has two sisters, but she is the one who is close to their father, Mavis has several sisters, but among these she and Mary have always been close. Along with birthplace within the family and geographical distance there was obviously something different in the nature of these relationships. Finch and Mason (1993) who looked at the meaning of family responsibility found that 'sense of responsibility for helping someone else develops over time, through interaction between individuals involved.' (Finch and Mason 1993, p.167). Thus one daughter may have accumulated a more extensive range
of commitments than her sister. This commitment will then become consolidated once a woman begins to undertake a particular caring path.

Unlike the other women in the study, Rose actually felt her brother was probably more patient and caring than she was herself:

"he's very sweet, and very caring, and everything he can do he does"
[Rose 1 p.4]

It is difficult however to establish how the experience was different for the male and female relatives who took part in this research. Finch and Mason (1993) believe that it is too simple to say that men and women have a different set of moral values. They argue that because of the different conditions under which women generally lead their lives it is more likely that a process of reciprocal responsibilities with kin will have accumulated.

The issue of gender is further discussed in the final chapter. The male participants were a small and not very homogeneous group. Robert, the youngest participant, appeared the least involved in the patient’s illness and Geoffrey was quite severely disabled. Except for these two, the others all appeared very willingly to take on a supportive role with their partner some men taking on tasks which might previously have been outside their ‘capabilities’. In relation to the taking on of protective strategies and caring roles there did not appear to be a striking difference between male and female participants. Contrary to stereotype, men did not appear to be more protective or less caring. Nevertheless, unlike the women they had few other domestic commitments.

SUMMARY

Some of the changes in the interactions between the person with cancer and their close relatives have been illustrated in this chapter. This usually required putting what they perceived as the patient’s needs before their own and attempting to protect them from exposure to potentially distressing situations. This had an effect on communication and
possibly heightened feelings of isolation for all involved. There was an increased need for practical and emotional support for the person with cancer and although all relatives believed that they should give this, in some instances life circumstances or a more complex relationship with the patient made this difficult. For many however, the need to care was integrated to their self-identity and it gave intense satisfaction to be able to help the person with cancer – for some this was an important element of being able to get through this experience. The need to ‘do’ something to combat the more existential concerns was illustrated by the (often stressful) attempts to feed the patient and in the frantic cleaning undertaken by some to get through a difficult time.
Chapter 7
THE EXPERIENCE OF CONTACT WITH THE PROFESSIONALS
INTRODUCTION

This chapter describes the relatives’ perceptions of, and interactions with, the health professionals and the surrounding influences on these. The contact between health professionals and the families who took part in this study was infrequent despite current philosophies of care. The Royal College of Nursing’s Standards of Care for Cancer statement on family care is:

"The family of the individual with cancer is prepared and supported by the nurse and referred to other members of the multi-disciplinary team where necessary to adapt to the changes throughout the course of cancer." (RCN Standards of Care Project 1991, p. 9)

Several studies aim at identifying the most vulnerable family members who might need professional intervention (e.g. Kissane et al. 1998). Support groups for those close to the patient have been found to be a safe arena to express emotion (Wellisch et al. 1978) and for sharing experiences and developing skills (Code and Paul 1999). But these are by no means universal and are only acceptable and suitable for some. The discussion of social support in chapter two has illustrated that much of the emphasis on support for the family is underpinned by a belief that this is a crucial element in providing support for the patient. This is clearly important, but it does not fully address the relative’s own needs.

Contact between the relatives and professional carers cover a broad spectrum of situations, including patient investigations and information about results, hospital in and out patient treatment and community care from nurses and GPs. The professional carers’ styles of communication with the family may influence how the family perceives the cancer. The personalities and skills of the doctors and nurses involved as well as the structures within which they worked are obviously essential to the relatives’ overall perceptions of their interactions with them. However, the relatives’ own experiences and reactions to the situation also play an important role in the patterns of communication developed between a family and the professional carers.
The emphasis of this chapter is not to be critical of professional hospital and community care, but rather to show how it was perceived by the families and why in so many cases they remained uninvolved with it. Several factors have been identified in the analysis which might result in relatives being “invisible” to professionals. For example, the patient themself may block their family from having communication with professionals. The relatives may have their own health problems which inhibit them from leaving their home. Fear of learning about what was happening with the patient may also keep them away from hospitals and clinics. Lack of familiarity with the health system or other life commitments may prevent those close to the patient from being able to speak to the professional carers. Most of the families participating in this study preferred not to have outsiders in to help at home. Some did not react to the illness in the way that professionals might expect or even want them to. Indeed many of the relatives would have been unable to express what their own needs or requirements from the doctors and nurses might actually be, given that it was not they themselves who had the cancer.

The relatives’ central concern for the patient’s well-being meant that it was difficult for them to consider their own requirements for help as distinct from those of the patient’s. When the relative felt supported this was usually when they believed they were being helped to support the patient rather than actually having their own needs addressed. Poor attention to patient care was a source of exceptional distress. As Debra commented:

“because although Peter is one person.. we are.. I don’t know, it sounds stupid.. but I mean if he was being treated badly, I would have been treated badly... it’s as simple as that.”
[Debra 1 p.10]

When writing about interactions with the professionals it is tempting to try to engage the reader with a gripping catalogue of incompetent and damaging behaviour. However, much of what the participants said about the healthcare workers in this study was actually rather bland, perhaps reflecting the fact that the participants were conscious that
I was a nurse along with the fact that they felt there was little to say about the professionals with whom they had had so little contact. Here it is the omission of comment about the professionals which is so telling. For the relatives who are in such a vulnerable position, being critical of those upon whom one is so reliant is potentially a source of anxiety. Furthermore, although I assured the participants that that I had nothing to do with the patient’s care, my initial letter did mention the patient’s consultant’s name and thus a permanent connection may have been made in their minds.

The experiences of these participants’ contact with the health professionals are introduced by examining reports of what the relatives experienced as “good” and helpful care for both themselves and the patient, followed by describing the relatives’ reactions to perceived poor care.

ACCESSIBLE AND APPROACHABLE PROFESSIONAL CARE

Along with comfortable physical care, the key qualities praised by the relatives in the professional carers was approachability and accessibility. For some of the relatives where it was possible for them to talk to someone about their concerns about the patient, this seemed to make the experience easier. For example Norman, who despite his wife’s difficult illness and eventual death could not praise the staff who looked after them both enough. He was able to acknowledge his anxiety and uncertainty and he found support from the hospital doctors and nurses:

“but once again you were worried, I was worried, I used to knock on the door and say, can I speak to you sister? And then she knew I was serious because I called her sister.. and we’d sit down and I’d say.......... and I’d get this lovely common lecture.. you would understand it.. my little three year old would almost understand it they made it so explicit and I loved the bit by the surgeon.. used to come round, sat beside the bed with you, in the company with one of the sisters... or the staffs, and the staffs were just as knowledgeable as .. I never saw any difference”

[Norman 1 (tape 2) p.20]
It was when the patient came home from hospital that many of the relatives felt most isolated and worried. However Norman still felt that he had the support of the hospital even after discharge. He described his feelings of security despite being at home:

“I’m still only a bleep away from knowledge”.
[Norman 1 (tape 2 p.21]

This was some months after his wife had left hospital. The benefits of access by telephone were echoed by other relatives. Andrea described the experience:

“we’ve been extremely lucky with the hospital we’re at.. I know if ever I want to phone them, any time, they’re there, ......I think to know that you can actually phone them and you know who you are talking to.. by face, is very important.. particularly this problem, because you want to relate to somebody that you know. So I don’t think we could ask for any more from the hospital really. ......you get phone calls from them asking how he is, which I’ve never know before... so no. I can’t really speak highly enough of them, brilliant.. yes”.
[Andrea 1 p.21]

Longitudinal studies of distress following discharge for surgically treated cancer patients and their partners found that spouses had a consistently higher level of emotional problems than the patient - peaking at 60 days. For the majority this continued to be troublesome for six months after the patient returned home (Oberst and James 1985). The telephone has been described as a ‘tool of the trade’ for specialist paediatric oncology nurses, whose work is primarily focussed on bridging the gaps in care, particularly between home and hospital, for children with cancer and their families (Bignold et al. 1993). This was shown to be a source of comfort for the parents of children with cancer, and something that is more rarely available for the families of adult cancer patients - unless they are terminally ill. Andrea still felt appreciative of the hospital care even after her husband died at home. Her husband’s death was sudden and traumatic. She was impressed by the prompt contact the hospital made with her after he died, although she admits that she herself was not actually given much support in her bereavement.
Hospital outpatients were a considerable source of stress for both patients and relatives. Just under half of the relatives were able to attend at least one outpatient appointment with the patient. Of those who went in to see the doctor with the patient there were several comments about how beneficial it was to be included in the consultation:

“she [the doctor] was very.... it was very reassuring. You know, I felt, well I felt a bit better you know, hearing from her as well. I mean I know like you get it second hand from George”
[Georgina 1 p.5]

All of the above comments were made by those attending one particular hospital unit and it is possible to identify one nurse and one hospital consultant as being particularly skilful, with the hospital providing a supportive environment. This is obviously an important point. However, there were also other families who attended this hospital (and even saw the same doctor) but slipped through the net of support to become very isolated, with little professional help from anywhere.

Most relatives did find it helpful to go into the consultation with the doctor. However to be actually asked in to attend was mentioned as a signal that something serious must be wrong. Melvin attending for a six week post operative follow up appointment with his wife, both unaware that she had cancer, explained:

“the wife went in for her appointment, and within a few minutes she came out and.. said.. “he wants you”... and then I knew”
[Melvin 1 p.7]

Health care workers may also inadvertently over-involve relatives, perhaps not knowing the details of a relationship and assuming that the relatives will also have the professionals’ own ease with the intimate details of the patients’ treatment and condition. Elizabeth explained how embarrassing this could be:

“and then the doctor came along and he wanted to have a look at the colostomy, and he said to me... “I suppose you’re used to seeing this”, well I’ve never seen Bernard’s colostomy, and I kept saying.. “I’m only his sister,
I thought perhaps he thought I was his wife, so I kept saying, no, well actually I'm only his sister, but he seemed to regard that as... well that's no reason to leave the room.”
[Elizabeth 3 p.9-10]

The patients in this study were treated in a variety of settings. Two of the participants, whose partners were moved into the care of a specialist oncology department, felt that here they were both better cared for and their concerns better understood than they had been before the patient was referred:

"The...staff are more aware ... of the feelings of people and they've got the time ... maybe they’ve got the money in the department. whereas in an ordinary ward they don’t seem to have the time to do it, do they?"
[Ivan 1 (tape. 2) p.1]

Jill had had no contact with the health professionals throughout Jack's illness. However, when he was admitted to the hospice she found she herself was cared for, fed and supported:

"anybody who is frightened of going in there, if they know.. they shouldn’t be because they are so lovely people, they really are, they’ve got the patience of saints”
[Jill 3 p.14]

Discharge home was a time when the relatives became very concerned about their responsibilities - particularly as several complained that the patient was discharged home too early. Nevertheless, there were instances where the relatives themselves did feel cared for. Doris explained how she herself was comforted by the district nurse. The nurse was someone who she felt accepted her and who she could tell her worries to. The nurse was able to provide some feeling of security for Doris who was feeling very insecure as a result of her husband’s cancer and its treatment:

“But then the district nurses came and oh one of them she was a gem, she was really lovely. So I began to, I don’t know, look upon her a bit like a mum, you know because she was very "mumish". I mean I am a
grandmother, but I think you do perhaps look to somebody else and she was such a comfort”.
[Doris 1 p.7]

Macmillan nurses visited two of the patients who were seriously ill at home and their support was seen to be invaluable. Norman was helped by the information she provided them,

“She comes and chats... she generally calls on a Friday afternoon, and she’s very helpful... answering questions...”
[patient adds] “very knowledgeable... on the subject... you know.”
[Norman 1 p.19]

However, Jade had the Macmillan nurse stereotyped from earlier experience:

“and they always near enough dress the same... in a plaid skirt, with a blue cardigan with a badge on it, cos I’d seen lots of them at Y hospital.............
I saw this woman in a pleated, plaid skirt, blue cardigan with a badge on it, and I knew it was gonna be bad news”
[Jade 1 p.24/25]

The participants were more often appreciative of the nursing rather than the medical care. However whereas the interactions with doctors were often remembered in detail and their consequences had considerable impact, the nurses were generally remembered as “lovely” and “nice” and there are few accounts of individual communication with them:

“But the people in that hospital, they were so lovely... all the nurses... and that... all had a smile on their face”
[Debra 1 p.5]

In Hull’s (1991) study, families of terminally ill patients identified four key areas of caring by the nurses. Twenty four hour accessibility through rapid response to telephone enquiries was much appreciated in reducing anxiety and uncertainty about what to do. Effective communication skills were valued, the ‘calm and unhurried’ (p.67) approach
that the hospice nurses adopted with time to talk and listen when the family wanted this. The nurses were described as having a non-judgmental attitude taking their cue from the family about how they felt about the situation and supporting them in this. Finally, clinical competence was seen as essential. Some of this behaviour was contrasted with the hospital nurses who were perceived as being more rushed. This study gives a very positive view about those elements of nursing which make the families of very sick people feel cared for. The analysis of the experiences of the families in this study as presented in this chapter would support this, and what follows also gives some indications to professionals about why this may sometimes be quite a complex and difficult task in which to succeed.

Even when the family was pleased that the patient appeared to be receiving what the family perceived as good care, this care may not be extended to the family members. Indeed there are accounts in this study by patient participants of how well supported they were by the hospital department where the relative had had no contact whatsoever. Bernard who as a patient had treatment in a specialist centre for his cancer described support he gained from conversations with his doctors:

"when you’re faced with an illness that you can do nothing about and it has the potential to kill you, it’s not like a broken leg which is going to get better, you are wholly in the hands of the doctors and their attitude is of paramount importance to your own feelings about what you’re going through ... and the attitude at the hospital was superb, it was all hopeful and you know, things to be done and of course they were carrying on the treatment"

[Bernard 3 p.1]

However, Elizabeth his sister, when interviewed in the same week, described her own relationship with the health professionals with whom she had little contact:

"I still think doctors and nurses are treated as if they’re almost god, I still think there is that feeling, although we’re meant now not to be impressed by these things.. we are. You still tend to think.. you don’t think of them as another human being who I can talk to.. like you might talk to the ticket collector at Balham tube station.. you do tend still to have this feeling that
you should be looking up to them, you know they’ve descended from some dizzy heights”
[Elizabeth 3 p.27]

Elizabeth recognised that there was not meant to be a social divide between the doctors and nurses and those they care for but nonetheless for her it was there, and as a relative she could not breach this. Elizabeth did recognise that she herself needed support but did not think of getting it from the hospital. As will be addressed later in this chapter she remained unfamiliar with the healthcare system. Doreen, who was extremely pleased with the care that her husband had received at the hospital describes her situation:

“I can’t fault the care that he had, at all.. or even... I can’t say that I really had any support, but I think had I needed it, I could have got without any problems”
[Doreen 1p.3]

Like many of the relatives who see the patient’s well being as the priority, Doreen did not think that she herself merited any support from the hospital. Nevertheless, in the next few sentences she describes her own intense anxiety when the nursing staff failed to inform her of what to expect of the usual post operative procedures.

THE REACTION OF RELATIVES TO PERCEIVED POOR PATIENT CARE

The relatives also reported incidents of difficult or complicated experiences with health professionals. These were sometimes problems with individual professionals, particularly over consultations with medical staff. There were also grievances about what the relatives saw as poor care. These accounts usually related to issues which the patient encountered rather than with the relatives’ own personal complaints. However, this could provoke difficult emotional reactions. All these problems were worse where the relatives saw the staff as unapproachable or inaccessible, whether it be in relation to getting a bed changed or wanting to discuss the patient’s prognosis.
There were several reports about poor general care which led to feelings of anger and disappointment:

"but there was one day I was there, and he was... the tears were rolling down... he was in so much pain... so I asked somebody if maybe he could have a tablet or something, or an injection and they said later, later, they couldn't give it to him yet. He hadn't had one... and because he is such a proud old boy, he would rather suffer the pain than ask for it. Anyway a couple of hours later I'd come back he was still in terrible pain and I asked... but I suppose the discipline isn't there quite as it was... going back years. But I did find that, and he asked for a blanket and... it's all cos they're understaffed, they just haven't got the time. And I find it very traumatic, being in the ward with a lot of them in pain..................

HP. Just going back to the time in hospital, how did that make you feel?

Oh well, I felt quite angry about it, but also the other side of me said well, they're doing a fantastic job, because I wouldn't like to have to... do what some of those nurses and people do. But I just felt them totally unsympathetic, but whether that was because I was at a vulnerable stage, you know, and I'm thinking well why does he have to be in so much pain... but there's good and bad, isn't there."

[Betty 1 p.7]

Betty was very distressed about the 'care' that her father was receiving from the hospital. Nevertheless she felt she had to qualify this for the interviews by saying that the nurses were doing a 'fantastic' job and that they were very 'busy'. She also tried to put some of the blame for this on herself for being, 'at a vulnerable stage'. This may be because I myself am a nurse or that she felt it was not right to be critical of the professionals who had looked after her father - in practice they obviously were not doing a fantastic job.

Mary was unqualified in her anger about the physical environment her sister experienced post operatively. She complained about the fact that the ward was not cleaned, that they forgot to feed her sister and that she herself was unable to find out any details of her treatment.
“and she was sat on this old armchair... I mean it was really a scruffy old armchair, and she had her drip and her urine bag ....... and her little feet was all swollen up and the ward was filthy........you could smell it... and I asked for a stool, a simple thing like a stool and a blanket, to put her feet up.. and they didn’t have any...”

[Mary 1 p.3]

Lack of comfort, dirty wards and poor quality food which was often attributed to lack of resources, was a source of distress to several of the relatives.

Furthermore, the need to see that something was being done to help the patient was very urgent for some. Terence describes how difficult he found it to watch the management of his wife’s chronic bowel obstruction. He did not understand why the staff had to keep changing her treatment:

“I mean even then I was doing me nut really.. they wasn’t doing.. they was just putting her on the drip, taking her off the drip, then putting her on a light diet.. then ..been the toilet, no... take her off the light diet, put her on water again, on the drip. I don’t know. It didn’t seem like they was doing anything to her. I mean that”.

[Terence 1 p.6]

Projection is a mental defence mechanism described in psychodynamic theory (see Theoretical perspectives on the family in chapter 2). Barraclough (1994) describes patients being irritable with their relatives ‘because they are not aware of their own sadness, fear or anxiety regarding their disease.’ (p.41). Anger may be displaced towards healthcare staff, for example, one might get angry at the person who is giving the bad news or “gatekeeping” the system:

“I was fucking wild.. I could have killed that receptionist.. she said “oh hang on, hang on...”

[Mary 1 p.16]

Judith felt physically violent towards her father’s family doctor. She describes her desperate attempts to get the GP to pay attention to her father’s distressing symptoms. Judith spoke at length and with great anguish about this episode:
"I mean it was the shoulder, he was in agony. He couldn't eat, he couldn't drink, he was just laying in bed wasting away. He didn't wee or anything for days, because he hadn't taken anything in. I mean you could just look at him and see he was dying, and I was backwards and forwards up the doctors... but she just... I don't know... she just kept saying quite casually... "well he hasn't got long... he hasn't got long". So I said, well you just can't leave him there like that... and then in the end I went up there and I just went in front of the other patients and said to her... well you've got to come out... you must come out. I mean to see him laying in bed crying... so in the end I did, I just sort of dragged her out and made her come round."

As the GP. was able to do little to relieve Julian's symptoms when she saw him, his daughters asked if their father might be admitted to hospital:

"I mean she got on the phone... so she said... "I'm a GP, yes, I quite understand... no beds..." and in the end she put the telephone down. And I said, but you didn't explain what he's like... you didn't tell 'em that he can't eat, he can't drink... he's got to have radiotherapy on Monday, you didn't tell him that, so she said "well there's just no beds". She said... "we'll try and arrange to get a nurse to come out", so I said, when, when? What do we do with him in the meantime... and I mean I wanted to pull her hair out... but all she wanted to do was get out the door, and in the end she went out the door. So I mean I was pacing the floor, I said to me sister, what are we gonna do? So I phoned the hospital and I explained to them, so she said... "yes, bring him straight in...".

And the next day when his daughters visited:

"When we got up there, well we couldn't believe it... couldn't believe... and he was saying "and I'll have some pears and I'll have some bananas... ". I mean he hadn't eaten for weeks... he was like a kid... he said "look at me, I can move me arm" and I said to me sister, why couldn't they have done this, why let him suffer... all that time. And he could have been like this. Alright, if he's gonna die, but don't let him die in pain."

[Judith 1 pp. 7-9]

This intensely difficult experience of watching someone that they cared about in discomfort was in some instances made very much more difficult because of professional inadequacies. Kristjanson (1999) found that families who perceived that
The person with cancer experienced poor professional care experienced more health problems themselves. Kristjanson makes the link between the literature on the impact of stress on health with how a stressful experience of caring for someone with cancer may also lead to a deterioration in the health and well-being of family members.

The difficulties of watching a loved one suffering without being able to do anything have been discussed earlier. Jackie described how hard it was to see her husband suffering when there was only a vague promise of relief through further treatment in the future. She was not angry at this time, but she describes her own emotional pain of watching Jonathan suffer and not understanding why more could not be done to help.

Ferrell and colleagues (1991) in their study of the impact of cancer pain on family caregivers found three major themes in response to a question asking what was it like to have somebody they loved in pain. The first was ‘helplessness’ which Jackie clearly illustrates:

"And that’s the hardest thing to do, is to sit and wait, and to watch"
[Jackie 1 p.5]

Ferrell et al, found that their participants also coped by denying their own feelings which is also a central issue running through this work. These authors final theme was a ‘wish for death’ which was expressed by only a very few of the participants in this study (see Watching and waiting, chapter five) and is associated which the very advanced disease which these particular patients were experiencing.

Jackie was upset about the confusion and lack of continuity in her husband’s care. She looked after her husband at home before he died. This was what they both wanted. She explained that a nurse had called, but frightened that her husband may get taken into a hospice against their wishes she had told the nurse that she did not need help. She describes her agonies of indecision, wondering if she was giving the right care or not, whether or not to call for professional help but not wanting to bother them. She felt she bore the responsibilities for his care on her own:
so I found myself reaching for the phone ... getting ready to phone for the district nurse, but then thinking, should I, shouldn't I?

I was worried, can I be doing any more for him, so if somebody had just like come or phoned, and said. “how are things.. it's three weeks since I last come, I know you said you don't need no help, but how are things? right?” And then I could say. “oh well by the way.. he's got such and such a thing at the moment, is that all in order.. do you see what I mean?”

[Jackie 2 p.28]

Taylor et al (1993) who explored issues of managing cancer pain at home, found that the decisions and conflicts most frequently arising for the caregivers were related to medication, particularly when and what to give. This often left the carers wondering if they had ‘done the right thing’ (Taylor et al. 1993, p.923). In Jackie’s case, the nurse and doctors seem to have known about the situation but did not offer any help when they were not actually asked for it. Jonathan died a most traumatic death at home, the tumour in his lung eroded a blood vessel and he bled to death over their bedroom. Afterwards Jackie did not receive any professional comfort during her bereavement when she found that all her habitual support systems also failed her.

Poor patient care aroused difficult emotional reaction for the relatives. This was often hard to express because of their own insecurity in the situation, and their dependence on the health service for support.

**Delayed diagnosis**

For many, the time around the diagnosis was the most difficult time. The patient and their family often felt particularly vulnerable at this acutely uncertain stage of the illness. Strained relations with professionals, particularly if these created a delay, made participants resentful and cast shadows over any future relationship.

Debra explained that she did not think her husband’s symptoms could be serious because of the GP’s apparent lack of concern. Her own first reaction had been to think of cancer, but she dismissed this because the doctors did. For several of the participants the period
of time from first noticing symptoms to getting a diagnosis of cancer was quite protracted. Jade recalls:

"it seems unbelievable that when a 64 year old man is coughing up blood that a chest X-ray isn't routine. It might have saved his life. I'm not saying it would have, but it might have done, but she didn't. She sent him away, and of course, after a year... of coughing up blood, not a lot, but some... he got so ill... so he said "alright, I'll go for an X-ray"

[Jade 1 p.6]

Looking back Jade blamed herself for not going to the doctor and insisting that something was done earlier. Several relatives did feel that it was their responsibility to get the patient to the doctor to find out what was wrong. Betty remembers that her father was sick for a long while before he was diagnosed with cancer:

"Well he hadn't felt well for a couple of months, and... so he went to the doctors, and they really diagnosed him wrongly, thought he didn't have enough iron"

[Betty 1 p.1]

Her father's condition became worse rather than better and although her father did not like his family to fuss about him they decided that they must intervene. This was done behind Bill's back:

"I just said oh well, well, ... go back to the doctors again, but also my husband rang the doctor, without him knowing and said that we weren't really happy, could they see him again"

[Betty 1 p.1]

Doreen whose own cancer had been misdiagnosed did not trust the GP at all when her husband had suspicious symptoms. They believed that they had to bypass their own doctor in order to get a diagnosis:

"but I mean to go to the doctors that we were under at the time really was a waste of time. because I knew from personal experience that they weren't really sort of very helpful, you could diagnose your own ailments easier than what they bothered to"
Stephen referred to the delay in Karen’s diagnosis several times in his interviews. The delays were in part administrative, but the couple remained resentful that Karen’s suffering did not seem important enough to acknowledge:

“And she was being passed from one to the other and there were enormous gaps then in that they lost her papers for something like two months, one writing from one to the other. And this we were both very, very annoyed and upset by this time but of course the thing that comes in then is that you feel you don’t want to upset the person who is in charge of your treatment. So you don’t feel that you can do anything about it.”

This couple knew that early diagnosis was important for the successful treatment of cancer. However, despite this threat, their relationship with the doctors felt too tenuous to be able to challenge what was happening. These feelings of vulnerability experienced by both patient and relatives contributed to the ways in which they remained unacknowledged by the health professionals.

UNAPPROACHABLE AND INACCESSIBLE - LACK OF INFORMATION

Many of the relatives found the professional carers difficult to approach. This is indicated by how few substantial conversations with them were reported in this study. This was for a variety of reasons, some of which were to do with the relatives’ own circumstances. There are of course also ethical problems with discussing the patients’ condition with a relative without the patient’s consent. Furthermore in this study some of the relatives were blocked by the patient from obtaining all the information that they felt they needed.

However there are some instances where the difficulty appears to be created by the professional and the participants made some illuminating comments about this. Jade and Judith, both assertive veterans of the hospital system, found one particular hospital doctor difficult to communicate with successfully when they attended the outpatient
department with their father. Jade’s commentary on his behaviour gives a clear idea of what the consultation felt like:

“He’s not nasty to you. It’s his attitude... he doesn’t look at you, and when someone doesn’t look at you you’re very wary of them... he doesn’t talk to you he talks past you... that’s if he talks to you at all... and he sits there smiling while he’s writing, and you think is he writing a dirty poem, and he’s smiling about it, is he very pleased that me dad’s got cancer, and he’s writing about it. He doesn’t put you at ease and he doesn’t talk to you, that is the main thing, and that is why you find him so horrible.”

[Jade 1 p.19]

Mary, who knew her way around the hospital system, described how she tried to find out what happened after her sister went to surgery:

“And course nobody would tell me anything, and I said look I’m not gonna go till I see somebody. And then I waited a long time in the corridor, mind that’s like Piccadilly Circus, and this silly sodding student doctor came along... I know he was cos I seen him trailing with these big nobs... and he left me in the corridor. Wouldn’t you say ‘I’ll take you in an office?’ I mean and everybody walking past. He didn’t know where to start... I said ‘I want to know exactly what’s happened to my sister’, so he said ‘well... we took the ulcer away...’ I said ‘yes’, I said, ‘how about the cancer?’... ‘oh’, he said, ‘it was only a little one, and that’s all taken away’, he said,”

[Mary 1 p.5]

Doctor’s lack of experience and uncertainty about how to talk with the relatives featured in several of the accounts in the research. Most of the problems seemed to be about giving information, particularly the diagnosis:

“the locum [doctor] there said, you’ve had your bronchoscopy, we can’t really tell exactly what’s wrong but we’ll recommend you for ray treatment. So there we were like that, you know. So we was wondering what was going on. But anyway we eventually found out it was a tumour.”

[Jackie 1 p.4]

The ‘ray treatment’ that the doctor had recommended is only used to treat cancer and yet it was not until two weeks later that this couple were eventually told that the husband
had a tumour. The doctor's failure to inform them of the diagnosis caused further distress and loss of faith in their doctors. As Jackie later said:

"why do the medical profession think that you shouldn't know about your own body?"

[Jackie 1p. ]

Some participants tried to explain and understand the professionals' difficulties in talking to them about the illness and how stressful this could be for them. Ivan construed that it was the doctor's uncertainty about how the patient and their family would react to hearing the diagnosis which made them so cautious with the truth:

"Then we went in to see the doctor and he asked us what we thought about it, whether it was cancer and that... and we asked if it was malignant, which he was a bit dubious about answering, well I think they are, doctors aren't they. I've always said to my son, I don't think they realise, or they don't suspect how you're going to react, so they're a bit reluctant about telling you so I think they tend to try and draw it across from you rather than them telling you I think."

[Ivan 1 p.1]

Alison put it down to the doctor's need for self protection against constantly breaking bad news combined with the volume of work.

"The doctor was very abrupt, I suppose because that's the way he has to deal with things, I don't know... as were the nurses really, because there was an awful lot there, an awful lot of patients there"

[Alison 1 p. 8]

Nonetheless it was difficult for participants who were concerned about their relative's well being and trying to support them, sometimes from a distance, without having any clear idea about their medical condition. Alison eventually became very cross because there seemed no way that she could find out what was happening with her elderly mother:
“So yes, I was going round feeling pretty angry really. I tried once to make an appointment with the doctor across the road and I said ‘look will you just tell me what’s going on?’ And he did this act of .. standing behind this sheaf [of paper]. ‘yes, well I haven’t had too much time to look at these.. we’re sending her back to the hospital anyway’.. he said ‘she’s done very well, we’re sending her back for further treatment’ ”.

[Alison 1 p.12]

Lack of information from the professional carers is a common feature of many research papers concerning care of the family of people with cancer (Tringali 1986; Lewandanski and Jones 1988; Northouse 1988). There are obviously a whole constellation of reasons why this should be so hard for the professional. The most common reason that the professional themself might give (and this is derived from personal observatuion rather than from the professionals themselves who were not interviewed here) is a lack of time - and whilst this shortage of time is an indisputable fact, it also acts as an effective defence against any closer involvement with the process of care for any individual patient and their family.

Menzies Lyth offers an explanation from a psychoanalytical standpoint into the complex and sometimes troublesome relationship between health care professionals and the relatives:

“Relatives may also be demanding and critical, the more so because they resent the feeling that hospitalisation implies inadequacies in themselves.”

(Menzies Lyth, 1988, p.48)

As Lanceley (1995) drawing on Menzies Lyth’s work comments the projection of emotions from patients and relatives may be too much for anyone to deal with despite their skills, unless they themselves were ‘held’ in a supportive working environment. Even those nurses who may be skilled communicators ‘might block their own skills and use them inconsistently’ (Lanceley 1995, p182).

Jackie herself suggested that it was the fact that Jonathan had terminal cancer that made the professionals avoid them:
"And I’ve got a fantastic doctor, I really have, but he didn’t exactly come round either, unless I asked him round you see? It was as if, Jonathan’s got this, he knew what’s going to happen, that’s it.”

[Jackie 2 p.29]

INVISIBLE RELATIVES

A number of the participants (7) had almost no contact with the health professionals during the time of this study, others had only minimal interaction. This section attempts to disentangle some of the reasons why the relatives so often remained on the margins of the attention that the patient received. Some of this may be explained by a lack of facilitative skills in the professional, but this research also demonstrates the ways in which the relatives subsume their own role and needs within the illness.

The findings of this chapter are consistent with, and add to, other studies which explore why the relatives of adult cancer patients and health professionals might find it difficult to communicate with each other. Northouse and Northouse (1988), found that information was difficult for the family to obtain because of the nature of the professional-family relationship. Northouse and Northouse (1988) found three main reasons in the literature to explain this. Firstly, family members were seldom in the hospital at the same time as the doctors. Secondly, the onus on initiating contact with the professionals often rests with the family, and thirdly both professionals and family tend to play down the importance of the relationship between them - both seeing the patient’s relationship with the professional as the primary focus of care. Field and colleagues (1992) elaborated why the carers of terminally ill patients may have limited contact with hospice staff. These findings echo those of Northouse and Northouse (1988) in several ways and include: visiting in the evenings when a doctor was less likely to be available, the relative’s own unwillingness to approach staff, lack of time available to professionals and the fact that most time spent by the professionals with the carers was when the patient was severely ill (Field at al, 1992).
In a review of the needs of family caregivers of people with cancer, Laizner and colleagues include a table illustrating the barriers that prevent the family from gaining professional support. These include:

1) Lack of awareness about available services
2) Lack of knowledge about how to access services
3) Financial constraints
4) Stigma of accepting help
5) Family resistance
6) Transportation
7) Existing services are overworked
8) Health provider goals are not congruent with patient goals

(Laizner et al. 1993, p.118)

The barriers preventing communication between the relatives and health professionals in this study are not dissimilar to those of Laizner and colleagues, although transport and financial constraints did not really figure as a problem. In the studies cited above the patients would have been spending more time in hospital (or hospice) and the focus of the research is less concerned with provision of support at home. In this study issues that came up were more likely to be in relation to the relatives’ personal and social circumstances and their own reactions to the illness. Elizabeth’s comment goes some way to begin to illuminate this:

“You feel guilty because you feel that you need support, and you begin to think to yourself, well... goodness I haven’t got the cancer, why should I be looking for support, but in fact you need support, in a way as much as the person with it... they will get support, you might not,”

[Elizabeth 3 p.6]

**Putting the person with cancer first**

The notion that the relative’s might put the patient’s well-being before their own has been explored in chapter six. In situations where the relative had involvement with the healthcare professionals the situation was constructed by both so as to attend to the
patient's needs. In this the health professionals invariably (although sometimes unwittingly) colluded.

**Blocked by the person with cancer**

Several of the participants were quite actively prevented by the patient from communicating with the health professionals. There were a variety of reasons for this. In some instances it seems the person with cancer might have felt that it could disturb their own way of dealing with the illness to have somebody else involved in a consultation as a witness - potentially offering a different interpretation. On other occasions the patient blocked the relatives from news to protect them from potential emotional distress. Furthermore, some relatives found the patients' presence a block to asking question that they felt might be disturbing for them.

Samantha who had never been to a hospital appointment with her husband said that her husband would not let her come with him to the hospital because she might try and find out about things that he did not want to know about.

"He don't like me going in, cos he knows I'll ask a lot of questions"

[Samantha 3 p.22]

Some relatives accompanied the patient to their hospital appointment, but were not allowed to go in to see the doctor. Mary explained how she would like to find out more about her sister's illness. However, Mavis, the patient, was independent and private and did not like to feel she was being looked after by her younger sister. It seemed that Mavis wanted to show the doctor that she was well and was anxious that Mary might undermine her by asking questions:

"what I would really like to do, which Mavis would never agree.. I would like to go with Mavis when she sees the specialist and I would like her to let me come in with her, because she wouldn't ask questions, but I would, and she's too proud, she wouldn't let me".

[Mary 2 p.4]
The professionals’ focus on the patient might mean that the patient’s strategies for coping with the situation would be (not necessarily consciously) supported. The relative may be physically present, but the patient could still manipulate the situation so that it suited their own way of dealing with the situation. For example, Anthony was very focused on himself and his own illness - he never understood why I might be interested in interviewing his wife about her own experiences of the illness. Krishnasamy and Wilkie (1999) who surveyed people with lung cancer and their informal and professional carers on their perceptions of health care need, found that only 29% of the 209 patients questioned ‘stated that they believed their family or friends had particular needs in relation to their illness’ (Krishnasamy and Wilkie 1999). Anthony had been asked by the nurses post-operatively who might look after him when he got home. He told them that his wife would, but without consulting her. Anne recalls how she found out he was coming home:

“the doctor told him that he could come home, but he didn’t tell me, and I was going in three times a day .... and he didn’t say anything... and all of a sudden .. oh the nurse came up to do something.. so she said, “oh anyway, you’re going home tomorrow”, so I looked at him, you know... “I knew .. three days ago”, or something like that but he was frightened to say it.”

[Anne 1 p.7]

Anne explained that Anthony was so superstitious he believed that if he told his wife he was coming home then it may not actually happen. The hospital staff who were ignorant of this coping strategy must have believed that he told his wife what to expect when he was discharged home. However, they did not actually speak to his wife who spent most of the day at his bedside. Anne was very squeamish, and in the event she had to change her husband’s dressings with her eyes closed.

Two of the patients when they were seriously ill at home tried to prevent their relatives from calling out the doctor or nurses to get help. Jackie explained how Jonathan did not feel he could tolerate any further medical intervention:
“then he would say, ‘don’t get the doctor out, you’re doing alright, don’t get the doctor out, I don’t want to see the doctor’.. he’d had enough, you see, he didn’t want no more”

[Jackie 2 p.28]

Jack, close to death, became agitated and also refused to allow Jill to phone for help:

“I’m so.. whatsit.. and he was.. he don’t want no one, wouldn’t have doctors in or any thing, you know... and I did call the doctor in at the end for him, to come and see him.”

[Jill 3 p.2]

Both these women were looking after very sick men under difficult circumstances. They were not unknown to the health professionals but the patients’ refusal to allow them to ask for help compounded their isolated situation. In all the instances mentioned above the person with cancer was very anxious about what was happening to them. They appeared to want to maintain as much control over the situation and flow of information as they could - it seems that they perceived involving their relative might jeopardise this.

Some patients made their relatives invisible by trying to protect them from difficult news and from seeing them when they were unwell. Like their relatives, several of the patients also tried to shield their family from unpleasant and emotionally difficult things. However, by so doing they may have also been shielding them from potentially supportive contact. There are degrees of protective behaviour exhibited by the patients. Georgina explained how her husband would not allow her to see him whilst he was in hospital having chemotherapy:

“and he said, ‘now I don’t want you to come with me in the morning’, so I said ‘why not?’ So he said ‘well, there’s not a lot you can do”

[Georgina 1 p.6]

This increased Georgina’s own anxiety but she recognised that he was happier this way and that he felt more ‘independent’ despite his illness, thus Georgina supported George to deal with the illness in his own way.
Alison found it difficult to understand and accept why the doctors would not speak to her. She thought one reason may be because her mother had forbidden them to:

"I don’t know whether they were being protective of me, whether my mother had forbidden them to, although I would have thought doctors should make up their own minds.. about what they say and to whom. I would have thought it wasn’t possible for my mother to have that much power.”

[Alison 1 p.11]

The relative’s need for information does present a problem if it goes against the wishes of the patient (which may or may not have been consulted here). Benson and Britten’s study (see The family and the professional carers, chapter two) found that the patients who they interviewed unanimously believed that their own opinion should take precedence over that of their family. Daniel, who had colo-rectal cancer wished to maintain his independence and also to protect his wife, explained how the worst thing for him was telling his wife the news of his diagnosis.

"Well no, the worst thing I think wasn’t me being told, it was the way of putting it over to the wife what it was... I had to tone it down a bit when I told her I think that was the worst part”

[Daniel 2 p.3]

I asked him how he toned it down:

"Well you can’t put much past her anyway (laughs) she knows me too well (laughs)...um... I didn’t mention the fact that it was cancer, just said that I’d got a thing in an awkward place that’s got to be removed”

[Daniel 2 p.4]

His wife on the other hand recalls:

"he sat down and we had a cup of tea.. and I said sort of.. well.. and he just said well they said that I’ve got cancer”

[Doreen 1 p.2]
This couple have a different recollection of the same event. It is possible that actually he did tell her straight that he had got cancer. More probably it was because his wife knew him so well that she understood clearly what her husband was saying in a rather veiled way. Krishnasamy and Wilkie (1999) found that 45% of their sample of informal carers of people with lung cancer were told the diagnosis by the patient.

A further difficulty for some relatives was that their only contact with the doctors and nurses was when the patient was there too. Several of the relatives wanted to plan for the care of the patient but really did not know how the disease was going to take its course. These were important but difficult questions to ask in front of the patient. Rose, her dilemma accentuated by the fact that she lived on the other side of the world, did not find the doctors sensitive to her concerns:

"not having the medical knowledge, I don’t quite know how much better she’s going to get....

I feel sure they would have answered anything I asked, it's just in front of mummy I didn't like to ask the things I really wanted to know... but they don't go out of their way to explain things... In fact they don't go out of their way to explain anything really."

[Rose 1 p.19]

Judith expresses a similar problem. They understand that their father will die but would like to have some idea of when and how. Most health professional are very reluctant to put a time limit on a person’s life - they may be wrong and a death sentence is difficult to live with for anybody - patient or relative. However, some indication of what is happening is clearly very helpful:

"it's awkward because me dad's always there... we wanted to ask... what will happen

I think we wanted to know... will it be quick... could this drag on for years... but I mean when they keep saying he hasn't got long, what do they mean?"

[Judith 1 p.12]
On the other hand, Karen, a patient who had always been accompanied by her husband to medical appointments, felt that as her disease became stable she now wanted to ask some difficult questions, but these might cause Stephen distress. Therefore she planned to exclude him from the interview at her forthcoming hospital visit.

“I find it more difficult to say what I want to say when (Stephen) is there and I don’t think he’ll come with me again, well I think next time I’ll say I want to go on my own, um...I mean I think what I’d like is for him to come with me and wait and come home with me

H.P. Why is that?

Cause I feel the things I want to say would upset him and I think that he’s been worried enough”

Karen 2 p.20

The belief by both the patients and the relatives that if a person is protected from knowing about something then they will be less disturbed threads through the interviews. There is little voiced concern about how uncertainty or lack of knowledge might affect the well being of those excluded from a more informed picture of the situation.

**Relationship with the person with cancer**

The individual’s relationship with the patient was obviously important in mediating the families interactions with the health care professionals and may also block access to support. Those participants who had a less easily identifiable public relationship, for example sister or land lady, rather than husband and wife were likely to have less contact.

Some of the situations which the relative’s found themselves in were very complex. Elizabeth described her brother as very private, not welcoming her company in hospital or at outpatient appointment. Bernard was very reluctant to pass on any news at all and Elizabeth had to follow a strategy of second guessing and gleaning information where she could. She felt he would be very angry if she told him she wanted to speak to his
doctor and yet she could not go behind his back. She also admits that she is frightened about what she might hear if she did speak to someone:

"you see... you walk this fine line of... if the patient doesn’t actually want you to know... that you’re almost going behind... I don’t think I would actually say to Bernard ... by the way I’m going to see the GP. this evening to talk about you. And I would feel I was going behind his back. I think that’s a very difficult problem...........
perhaps in a way it might even be a bit of self preservation there, I don’t know... you don’t really... want to... you’ll face that when it happens, perhaps you don’t need to be told in advance.”
[Elizabeth 3 p.21]

This creates a complex situation. No doctor or nurse will impart information against the patient’s wishes and furthermore, Elizabeth is ambivalent about what she wants to know. However, as it is, she is living and caring for someone, unable to make any plans of her own, with an anxious ill-informed, anticipation of what might happen.

**Relatives’ own well being**

The relatives’ own state of mental and physical health may mean that their experience of the illness was obscured from the health professionals. Geoffrey described his reactions to his wife’s hospitalisation. He believed that Hetty was being well looked after and said that he had full trust in her doctors, whose judgement he would not question. However, as he was visually impaired he could only visit the hospital when his son was able to bring him. The experience of being separated from, and worried about someone on whom he relied so much, whilst not fully understanding what was happening had a very profound effect upon him. He described visiting the hospital where, out of familiar territory, he felt extremely vulnerable:

"A combination of not being in control, and that’s the first thing, you lose your confidence, and if you’ve lost your confidence you’re like a little child, saying I want my mum, and there is no mum, so you’re sad and you give way.”
[Geoffrey 3 p.7]
Receiving no acknowledgement from his wife’s professional carers he explained how it made him feel:

“I could have gone off at the deep end, one hears about people in hospitals who go and rush into the casualty and thump the doctors, I can sympathise with them... because to them why isn’t somebody doing something, they don’t know what is happening, they see you’re calm and quiet, I sympathise with them. When you don’t know... this is... animal instinct. If you don’t know you bite it... or hit it or something, and I’m prepared to accept that... that when you’re reduced to the minimum, all you do is act like an animal” [Geoffrey 3 p.7]

Geoffrey could not visually understand what was happening with Hetty. Nevertheless, he would have appeared outwardly calm and quiet – his difficulties would have been difficult for him to express. He says that that he did not speak with any of the nursing or medical staff. After his visit to the hospital he described uncharacteristically ‘breaking down’ in the car park with his son, which he subsequently felt ashamed about. Hetty arranged all her investigations and hospital treatment around times when there would be somebody available to look after Geoffrey. Geoffrey was not consulted in this, indeed Hetty described him as being like a child. Hetty effectively blocked him from any support from the professional carers who, however unwittingly, colluded in this.

Julia was so disabled by cardiac disease that she had not been able to leave her house for two years and was unable to visit her husband at all when he was in hospital. She was also dependent on her husband for care. She relied on her daughters to give her information and it was they who told her that her husband had cancer. However, they were afraid that she did not understand what they told her. When I interviewed her she had not spoken to any professionals about the illness and had quite a muddled understanding of what was happening. One of her daughters’ greatest fears was that their father would have to go into a hospice and her mother would be forced to say goodbye to her husband before he went.

Doris found it very difficult to visit her husband in hospital because she was agoraphobic. She could only manage a few short visits to her husband’s bedside with her
daughter. Her husband was extremely anxious about his condition, but she was reliant on him for information about it which he was reluctant to pass on.

Some relatives were very inhibited by their own fears of what might be happening to the patient and this made it impossible for them to attend the hospital or talk to the doctors and nurses. During the interview with Jeremy who had lung cancer he talked a great deal about his daughter who provided him with practical and emotional support. Jeremy was unable to mention his diagnosis of cancer during his interview. His daughter in turn when interviewed was barely able to say the word cancer and spoke about how she could not visit her father in hospital because she was so frightened herself:

“I couldn’t go in, I just couldn’t. I spoke to him on the phone ... I used to phone him up and he’d phone me...but I’m a bit funny like that.”

I asked her the reason why she could not go and visit her father in hospital?

“I don’t know, they just frighten me... there’s just something about them, I don’t know what it is, I can’t handle it.”

[Jane 2 p.4]

The close relatives’ own anxieties about the illness could prevent them from asking for information even when the hospital facilitated their means of obtaining it. As shown in the section on physical manifestations of emotional disturbance (chapter five), hearing the diagnosis of cancer can cause an intense physical reaction which may often prevent coherent thinking or communication. Anne, was given a telephone number when her husband went to theatre for surgery and told to ring any time to see how her husband was. However, she explains that she could not actually make the phone call herself because she was too frightened of what she might hear. She was told:

“phone any time about six, or something like that” ... which we did, and I couldn’t make the first phone call, my daughter did.”

[Anne 1 p.4]
A past experience of hospitalisation or ill health could also make it difficult for the relatives to visit the hospital or hear about the illness. Isabel actually wanted her husband to go to speak to the doctors, with whom he had had very little contact, to find out more about her cancer. However Ivan found this extremely difficult:

“No, she kept on about me going down there.. but.. maybe I was shutting it out, I don’t know by not going down there.. perhaps I didn’t want to know.”
[Ivan 2 p.15]

And then he further explained that a traumatic hospital admission when he was four and a half years old had made it very difficult for him to subsequently have any contact with the hospital:

“I don’t like hospitals, no.. because of when I was a youngster, but .. me personally I don’t suppose there would be a lot anybody else could do, cos that’s the way I am in life.. and I ain’t gonna change, apart from trapping me in a room like, nailing me to the floor and saying things”
[Ivan 2 p.19]

These participants were not to be seen with the patient attending hospitals or clinics. They did not have difficult communication with the professionals because they had almost no communication at all.

Not conforming to the professionals view of what is best
In many ways all the relatives who have been described above were not conforming to a standard picture of the anxious relative at the bedside, listening to and absorbing information as and when the professionals considered it appropriate. Furthermore some of the relatives who did have communication with the doctors and nurses did not want to do what seemed to be expected of them, and thus distanced themselves.

Alison explained how she felt she could not spend more time with her dying mother after she had said goodbye:
“I was back home now, and the matron phoned me and said.. you really ought to come up you know.. and though I explained a little bit, she refused to see it from my point of view, and I said.. I’ve said goodbye, I can’t .. I just can’t. And she’d phone up every day and at one point my husband happened to be there, took the phone......[he said] ‘You really have to listen.. see it from her point of view as well’. But I don’t know she kept going on and on and on, trying to make me go, and she said .. ‘she’ll regret it if she doesn’t come, she really will’. To this day I don’t know why that lady felt the need to force me to do something which was patently beyond my own means”.
[Alison 1 p.18-19]

Alison’s own needs in these circumstances seemed to be subsumed in what the hospice believed would be ‘right’ for her. They seemed unable to hear her pleas that having said goodbye to her unconscious mother she felt she just could not to go back and sit with her again.

During the interviews some participants expressed anxiety about the emotional support offered by the professionals. Jill did not want the proposed support (bereavement counselling) after Jack died because she seemed in some ways to feel that she would not be able to do what they wanted her to:

“I don’t like to involve people.. or trouble people, I don’t know how you put it, whether I can’t talk to people so well in.. to explain them, I don’t know.”
[Jill 3 p.14]

She was also anxious about what might happen if she did start to talk about how she felt:

“I try not to show me feelings, a lot of it, and I thought well I’ll break down and that...”
[Jill 3 p.18]

And yet when she was asked how she felt after the interview during which she had been very tearful she replied:

“I feel fine yes, I do .. honest. Sometimes it’s better talking it out, more so with a friend.. your own you can’t say, cos you upset them or whatever... and .. sometimes it’s better to talk it out with someone else I think”
[Jill 3 p.22].
Andrea who also rejected the idea of bereavement counselling said a similar thing:

"like I talk to you.. or like we’ve talked before ... often... maybe it’s a good thing to talk to an outsider, somebody outside the family, because often you can get out of your body and your system, thoughts which you cannot express to your family"

[Andrea 2 p.29]

Perhaps it was what they thought counselling stood for that they found so difficult. It was good to talk to a neutral person outside the family, but they were suspicious of someone who did this professionally. Anne explained that talking about what had happened with a professional was not the way that she wanted to cope:

"I never discuss anything, well I’ve got nothing to discuss, come to that no good keep going back, is it? Once a thing is done, it’s done, it’s over."

[Anne 2 p.17]

The relatives’ own particular ways of living with the patient’s cancer, for example, by putting the patient before themselves, may make them less apparent to those trained to look after the patient. Kfir, a psychotherapist working with a group of relatives of cancer patients suggested that the relatives should respect themselves and take some time to rest (Kfir and Slevin 1991). Kfir reports on one of the relatives, Vera, who responded thus:

"I think you’re absolutely wrong. It’s impossible. I would feel very guilty because I was putting myself above somebody who was really sick. I couldn’t put myself in the role where my well-being was more important. I don’t think any of us could. I think that’s theorising." (‘Vera’, quoted in Kfir and Slevin, 1991, p.71)

Krishnasamy and Wilkie (1999) found that only 8.5% of their sample of informal carers would have liked professional help to cope with their feelings and concerns about the diagnosis of lung cancer. At the end of each interview in this study participants were consulted about a checklist of possible sources of support for themselves; support
groups, telephone help line and information leaflets (see Appendix). The results from this questionnaire showed that 11 participants had been given information leaflets or booklets at the hospital. None had consulted a telephone helpline. Elizabeth was the only participant who was interested in a support group - although she did not attend one. Other than this there was no interest in these services except from Jade who would have liked someone to come to her. Many seemed to concur with Georgina's view that, 'a stranger is a stranger' and that emotional support should come from the family. None of the participants had been seen by a social worker and only two by a spiritual leader, only one of them (Jackie) finding this helpful.

There appeared to be little attempt by the professionals to listen to the relatives in order to match up what support might be available for the families with what the family might actually find acceptable. For example several participants did not want to take up the practical help that the system might provide for them because they did not want outsiders into the house:

Georgina described how she would not want any help from outside to look after George because as well as the fact that she herself was helped by being able to care for him:

"I'm .. a bit too independent.. I don't want anybody coming in.... I value my privacy, and I think he does as well."

[Georgina 3 p.12]

Jade and Judith both comment on how their parents did not want outsiders to come in to help and Rose's mother also expressed similar sentiments. Williams (1993) comments that individuals with a chronic illness and their families may find the idea of dependence on others 'abhorrent'. Using an illustrative case from his study of the experience of rheumatoid arthritis Williams explains how 'Mrs. Fields' found help from mechanical equipment much easier to accept than support which involved other people over whom she felt she had little control. The first contact who I made for this study (who refused to take part but nevertheless kept in touch), explained how difficult both she and her
husband found staying awake in the evening waiting for the nurse to put him to bed. Eventually they asked her not to come anymore. As Samantha said:

“I don’t like people coming in and out, especially when you’re gonna drop off [to sleep]”

[Samantha 2 p17]

**Lack of familiarity with the healthcare system**

The requirement to learn about a new organisation and new people and new vocabulary at a time of fear and uncertainty was difficult for some. This feeling of being lost in the system, or ‘lost in a great machine’ as Stephen remarked, made the unfamiliar nature of the illness and its treatment worse. This was a difficulty for both the patients and the relatives - although the patient was often forced into a certain familiarity at an early stage. As the comparison between Elizabeth and Bernard earlier in this chapter has shown, for Bernard ‘the attitude of the hospital was superb’, whereas Elizabeth described them as ‘almost god’ and not like another human being that she could talk to.

Jackie described how the healthcare system felt for her:

“there was a lot of worries in the dark, not knowing what was going on and everything. But I’m not angry with no one, please don’t think I’m angry with anyone, but if things could have been different, I wish it had been different that way... you see?”

[Jackie 2 p.26]

Of course it was not just the relative who was unfamiliar with the system, particularly at the beginning of treatment:

“And I think it is a lot you’re left... he gets... you know this feeling, in the wilderness kind of thing... he says “I don’t know what’s going on like.. he says... is this alright in me that I’m going to go and it’s going to be too late, you know, for them to do anything, has it all started up again... that kind of thing. And mind you I’ve been... I’m the one that cheers him up then.

[Georgina 1 p.10]
Not having a clear plan of what was to happen next and not having being able to ask anyone for further information makes the anxious, uncertain time worse. Here Georgina believed she should take on the role of cheering up the patient and is thus unable to voice her own fears about the situation.

James (1993) reporting on an interview study about the care of the terminally ill comments that the 'unwaged carers' were absorbed into the hospital system when they were useful, but their support was not acknowledged by the organisation. Furthermore, when the professionals did not want or need those close to the patient then they were excluded from involvement (James 1993, p.101).

In this study there were only a few examples of the process of treatment being explained to the relatives, and the relatives rarely report their part in supporting the patient being acknowledged by the professionals. Even when this did happen as with Louise, where the medical staff made efforts to keep her informed because she worked in the hospital, she was unable to fully take in what they were saying to her.

**Life circumstances**

For several of the participants there were other concerns in their life as well as the well-being of the person with cancer which prevented them from being available and accessible to the health professionals. Young children could be a particular problem when trying to have any kind of dealings with the health care system. Debra wanted to go in with her husband to his post operative follow up appointment but explains how she was unable to:

"and then he [Peter] had to go back to see Dr S. to get the.. to find out what it was, sort of thing, and we had our son with us.. and I was waiting in the waiting room.. and he .. with Peter and he was just running riot.. he was just pulling everything apart, 'cos I did intend to go in with Peter .. and I didn’t... so I said .. I’m gonna have to go cos.. we couldn’t take him in there, cos we wouldn’t be able to listen to what he’s saying. So off I went into the car and ..I wasn’t really thinking the worst.. and Dr S. said to him.. it’s cancerous .. and it just knocked Peter for six, the way he actually said it to him” [Debra 1 p.5]
Judith explained how she often had several things on her mind at once and could not always be at the hospital when she wanted to be:

“then while I’m at the hospital I’m thinking.. I’ve got to pick him [son] up at half past three .. then I’m thinking ... god, right, I’ll have to arrange for someone to pick him up, then my sister is trying to arrange who is gonna pick her children up.”

[Judith 1 p.10]

In this study it was only rarely the demands of paid work which prevented the relatives from having contact with the professionals. The majority of the participants were retired, and where they were not as for example with Mary, Elizabeth or Louise or Ivan it was not their work commitments that kept them away from professional support. Furthermore, financial resources seemed to make little difference to the contact with the professionals.

There is a predominance of women in this sample, but, the men in the sample seem to remain as invisible as the women. In fact the few who really make themselves heard within the healthcare system are women. Distance could also make it difficult to make contact with the professional carers, for example, Rose and Alison both had this problem. The ways that life’s demands shifted in order to prioritise the patient’s illness was in part dependent on the severity of the illness and the relationship with the patient.

**Minimising the threat of the cancer**

As has been shown in chapter five, many of the ways which the relatives find to live through this experience involve minimising the disturbance caused by the cancer in their family life. Plausibly, this might involve finding out as much as possible about the illness and then being well prepared for all eventualities. It is undoubtedly a strategy used by some, but for a wide range of reasons, not followed by any of the participants in this particular study. The majority of these relatives managed by such strategies as keeping going, carrying on as normal and comforting themselves by thinking of those
worse off. These strategies were then unlikely to alert the health professionals to many of their deeper concerns.

James (1989) describes the day to day management of emotions at home as ‘listening, being there, talking and waiting mixed with giving direction, advice or actively making plans.’ (p.28). James believes that the value of this work is ‘hidden’ and its product is ‘invisible’ (p.28). She claims that minimal attention is made to such work which remains unrecognised when it is going well, and only commands attention on those occasions when there is a problem (James 1989). James develops this theme in later work commenting how feminists have described the work of carers as having been ‘invisible’, ‘because it was seen as women’s work, natural, to be expected, and hidden within the confines of the home by a society which emphasises status through waged employment.’ (James 1998, p.215). The set of relatives who took part in this study were involved to varying degrees in ‘caring’ activities which involved maintaining an emotional balance, preventing the fear of the cancer from overwhelming both the patient and themselves. For the majority of these relatives, with some notable exceptions, the nurses and doctors with whom they came into contact were not closely linked with this. The health professionals were more likely to be seen as a factor over which the relatives had no control, providing the ever present potential of disrupting the ways which the family found of minimising the effects of the illness on their lives.

SUMMARY

On the whole these relatives had very little interaction with professionals, and although the majority would have liked to be more involved they remained on the margins of the care that was given to the person with cancer. The participants appreciated when the health professionals were approachable and accessible, but found it very hard to tolerate witnessing what they perceived as poor patient care. Several factors were identified which may potentially make communication between relatives and professionals difficult to achieve. These included the fact that the relatives invariably put the needs of the person with cancer before their own as also quite naturally did the professionals. In
this study the professional carers only rarely made effort to support the family members, with suggestions made often inappropriate to the relatives' circumstances. The relatives' own state of mental and physical health could make it difficult for them to enter the unfamiliar healthcare setting and furthermore their ways of dealing with the illness, by minimising the threat of the cancer and suppressing their own emotional expression, might make their own needs for support less obvious. The implications of this for the professionals are discussed in the next chapter.
Chapter 8

LESSONS AND REFLECTIONS
INTRODUCTION

An important motivating force behind this project was a professional and personal belief that the diagnosis and treatment of cancer in a close relative or friend is a difficult experience for which it is unclear how professionals might best provide effective support. The study findings fully support this belief and in the final chapter the elements from which this experience is constructed are drawn together and reviewed.

The experience of each relative is unique. However there are common elements. The first section describes the inter-linking existential, emotional and practical dimensions of the relative’s experience which appear to apply to all participants whatever their particular circumstances. There follows a reflection on some of the contextual and social factors which influence these dimensions. These include the relationship with the person with cancer, life circumstances and gender. Such influences create the major differences between each experience. The effect of time and the cancer illness itself are also addressed as they have implications which are both common to the experience, but also create some of the differences. The second part of this chapter addresses some of the possible therapeutic indications from the work.

The research has illustrated how the relatives’ experience of the illness may remain ‘invisible’ in several ways. For example, along with the suppression of their own emotional reactions the relatives attempted to minimise the threat that the cancer posed. The person with cancer was most likely to dictate much of the way that the family lived with the illness and this in itself may have prevented the relatives from fully utilising their own strategies for living with this episode. Unlike the patient, the relative was unlikely to consider any potential benefit from the circumstance and it was difficult for them to find any sense of meaning in the experience. However, in the few interviews conducted after death, the bereaved relatives allowed themselves to more fully express their grief, and the experience became their ‘own’ story.
An unexpected finding of this work was the therapeutic nature of the interviews. These offered an opportunity for the relatives to tell their story and to be heard. The guise of doing something to help others in a similar situation offered an opportunity for reflection and acknowledgement which they almost universally said they would not have sought out for themselves.

The focus of this dissertation is on the experience of those close to someone diagnosed with cancer. Some of the findings may have wider implications. For example, the therapeutic benefits of listening, acknowledging and working with the relative’s way of ‘coping’ with the illness may also be relevant to interactions with the person who has cancer. Indeed, this may also have some relevance for the relatives of people with other chronic illnesses.

THE CONSTRUCTION OF THE RELATIVES’ EXPERIENCE

This section maps out the both the constant dimensions of the experience for the relatives who took part in this study and the variable influences upon this.

Dimensions of the experience

The dimensions of the experiences of these relatives are multifaceted and intimately interrelated. They should not be viewed as distinct entities, but in order to write about them they have been separated out.

(i) Existential shift

The majority of the participants in this study found it difficult to think carefully about what the diagnosis of cancer in someone close meant to them personally. For many, their world was turned upside down but they felt that their role in this was to keep everything going as ‘normally’ as possible, without revealing too much of their own inner turmoil. Nevertheless it was hard to express this, particularly if the person who was sick had previously been their closest confidante and greatest source of support. Most of these relatives, although they functioned within reasonably cohesive family
structures, appeared to be isolated in the situation. A small number of the women mentioned that the only source of comfort that they could think of was from their mothers - who were dead (this is called ‘regression’ by psychotherapists (Barraclough 1994). Giddens (1991) describes the interdependence of human beings required to create a sense of ‘ontological security’ which will ‘carry the individual through transitions, crises and circumstances of high risk’ (Giddens 1991, p.38). Much of this is acquired through the experiences of early infancy, which can create a ‘protective cocoon’ to life’s threats, but may also be a function of others with whom one has a long term relationship.

Bury (1997) writes that, ‘Existential crises, especially those connected with the onset of serious illness [which Bury has described as ‘biographical disruption’].....create a need for a more complete form of explanatory thought’ (p. 44). Bury is writing about the patient’s experience and he and other medical sociologists have explored how people may find meaning out of the experience of their illness. Here the close relatives experience an existential crisis with a threat to self identity and loss of control against which few factors mitigate. The relatives put the patient’s wellbeing first, submerging any addressing of their own needs, either because they do not believe that they have any or sometimes because they feel guilty. It was hard for these relatives to rationalise their distress in any way. Many found managing the emotional and practical issues arising from the situation in order to promote the patient’s well being was some comfort and the majority of the participants were in fact very resilient, findings ways of living with the illness by minimising the threat of the cancer. This undoubtedly helped them to get through this very difficult time, but other problems may result from their lack of self reflection.

‘The existential question of self-identity’ which Giddens (1991, p.54) sees as a dimension of ontological security requires a ‘feeling of biographical continuity’, which he believes is to be found ‘in the capacity to keep a particular narrative going’ (Giddens’ italics, p.54). In this study the participants’ ability to reflect on and construct their own ‘ongoing story’ was for a variety of reasons very difficult.
The people who took part in this study were still very much 'going through' the experience. The bereavement interviews recorded were not fully incorporated into this analysis. However, these interviews were different in nature to those before the death. In interviews after the patient's death there seemed to be a 'shift' back to focus on their own experience, with the relatives who were interviewed making their own story more central. They were then able to talk about their own experience and what it had meant to them and how they were beginning to attempt to reconstruct their lives after the loss.

The deaths were very difficult however, and all stated that they were worse than anticipated. None of the bereaved relatives who were interviewed could be described as having achieved a 'good death' as in the current modern western idea of it, whereby the dying person might attempt to shape their dying to positively affirm 'self-worth and social connection to others' (Field 1996).

Parkes (1972) describes 'deprivation' in bereavement which refers to the absence of love and security provided by the dead person. The participants in this study who were not bereaved had not actually 'lost' their loved ones, but were in some senses suffering from a deprivation of what they used to provide in their life.

(ii) Emotions
Emotions, expressed or suppressed in a variety of ways, are a feature in all the interviews recorded for this research. Difficult and distressing emotional events are becoming an increasingly acceptable area for academic study. Alongside the tools for measuring psychological distress the identification of the cultural explanations for emotional experience are proliferating. Furthermore, there is a growing field within sociology described as the sociology of emotions (Bendelow and Williams 1998). This is not a unified approach to emotional issues but generally aims to focus on the emotional elements of life rather than ignoring them. As Hochschild (1998) writes, 'Emotions always involve the body; but they are not sealed biological events' (Hochschild 1998, p.11). Sociologists of emotion are concerned with how emotions are
managed, the cultural medium through which emotions emerge, and aspire to developing theories of emotion.

For example, in research on family coping in childhood cancer, the complex and powerful feelings experienced by the parents are examined and the mother's 'close-up emotional engagement' role is explained by gender dynamics 'inscribed in dominant representations of caring as women's work' (Reay et al. 1998, p.39). This provides a clear explanatory framework as to how emotions might be managed by individuals, rather than merely attempting to measure their degree as a psychologist might do, but it does not elaborate the implications of the emotions themselves - the essential overwhelming love for the child that is central to these women. Indeed even now, accepted academic language does not lend itself to writing about emotional experience. Emotions may be explained, measured and even treated, but the elaboration of intense emotion belongs largely to literature and art.

Some of the emotions expressed during this current research were so powerful however, it seems that they themselves were part of the framework of this experience, and were the motivating force behind some of the behaviour of the participants. The emotions created the social situation. So for example caring can be a practical necessity which is often undertaken by women, but it may also be undertaken out of love and a need to do something when faced by uncertainty and helplessness. Putting the patient's needs before one's own is obviously because the patient's needs might be greater at that time, but is also motivated by powerful emotion that puts one's own well-being - albeit often temporarily - aside. The need to protect the patient may be because of avoidance of potentially difficult and confrontational social situations but also because it is perceived that it might prevent further hurt to the patient. The relative's powerful and ongoing physical reactions to the patient's illness will be exacerbated, or may be helped by the ways in which external events are managed. They are not 'biologically sealed' and are in response to external stimuli - but they can engender a reaction of their own. These emotions were undoubtedly influenced by many factors, but they were in response to the
fact that a loved one was diagnosed with a life threatening illness, and as such are one of
the fundamental dimensions of the experience.

Nevertheless, in these participants the situation did engender a belief that their emotions
had to be managed in a certain way and could not be given free reign. The majority
seemed to feel that they should not express their emotions, or at least they should be
careful about how they expressed them. A psychotherapist listening to me speak about
the study recently made a comment about the participants being in denial. I do not
believe that many of them were truly denying what was happening, rather they were
trying to manage their emotional response in ways which they felt were appropriate. As
James (1993) writing about the management of emotions during the disclosure of cancer
comments:

"Emotions can be regulated with varying degrees of sophistication and with
various outcomes and, like other skills, emotional labour requires flexibility
and adjustment. It involves anticipation, planning, pacing, timetabling and
trouble-shooting. Emotions that are not acknowledged – whether our own or
those of others – may be denied or suppressed, but full emotional labour
involves working with feelings rather than denying them." (James 1993,
p.95)

It is doubtful whether many people can truly work openly with their feelings without a
huge amount of intensive support. In these relatives there appeared to be a protective
suppression of their emotions in many of the social interactions, whereby feelings and
reactions to outside events were suppressed to a varying degree, in order to manage the
situation. So, for example Andrea or Georgina would have rarely given themselves the
opportunity to reflect on how very deeply disturbed they were by the situation, they
'coped' with both themselves and their partner's reactions by suppressing these feelings,
often quite deeply – whilst knowing that these feelings were there.

This was not really a 'disenfranchised grief' (Doka 1989), whereby a person experiences
a loss which may not be 'openly acknowledged, publicly mourned, or socially
supported' (p.4). The distress and grief of those close to someone with cancer would be
recognised as legitimate by society – although others in their social milieu would be most likely to put their concern for the patient first. However, as illustrated by the small sample here, those close to someone with cancer, whether it is because they are attempting to ‘be strong’ for the patient and others in their family, or striving to maintain a degree of normality, or because they were just trying to keep going, rarely let the emotion take them over so they could express how they truly felt. And if they did this was done in a controlled fashion.

This may have considerable long term effects. As indicated by Hochschild’s (1983) work discussed in the section on ‘Approaching emotions’ in chapter five, the managing of emotions may create two barriers – to reflection and to spontaneous feeling. Talking to my friend Paul Dennison, over six years after his wife Anne died, gave me a powerful and painful indication of the potential impact of this emotional repression, and just how difficult it was to support. He said:

“When Anne was sick I put all my feelings in a box. And I have never seemed able to get them out again” [P.D. 15. 11. 98]

(iii) Practical effects
The majority of the people with cancer involved with this study did not require a huge amount of practical care. Furthermore, there is an extensive literature on caring. Thus it was not envisaged the notion of practical caring would play a central part in the analysis of this study. However, whatever the physical state of the patient, the illness did require an often quite significant element of adjustment to the participants’ lifestyle, and many wanted to do as much as they could to ease the situation.

As, Cribb comments ‘Caring has both a practical and an affective side’ (Cribb in press). It soon became clear that in this study, the majority of relatives were involved (albeit some of them minimally) in both the more practical ‘caring for’ the person with cancer as well as ‘caring about’ them with an emotional attachment. What had not been anticipated was that these caring activities would for many of the participants be such a
source of comfort and self esteem. Commentaries on caring however provide ample explanation about why this might be. Benner and Wrubel (1989) write:

‘Being in the situation without caring robs one of perspective that only caring brings and renders the resources and meanings of the situation inaccessible’ (Benner and Wrubel, 1989, p.373).

This is an alternative reading to the ‘caregiving burden’ literature. It is not intended to deny the (for some immense) practical issues involved. There is undoubtedly a tension between the desire to help and care for somebody and the readjustment and disruption for life this involves. So, for example for Jade it was unimaginable for her to not practically support her parents, but it put a strain on managing the other responsibilities in her life – which was exhausting.

Strains were particularly evident in this study when the participants were not allowed to, or prevented from caring for the person with cancer in the way they wanted to, as in the case of Elizabeth or Alison, or when separated by distance or other life circumstances. Louise thought she should care, but felt resentful because of the other calls in her life and thus she felt guilty. These participants were denied the potentially satisfying experience of being able to ‘do’ something to help their relative.

This account might be perceived as presenting a rather rosy view of the practical issues of caring and not being fully representative of the complex and difficult reality of what caring may involve. However, this study does not represent a group of people who had chronic long term physical health problems which required a great deal of daily practical management. It was likely that these patients would either die relatively soon or remain reasonably well. This interpretation is also influenced by my own personal and professional beliefs, and probably does run counter to a culture which celebrates the success of individual achievement (Benner and Wrubel, 1988).

(iv) Time and cancer – common features
Two facets of the experience which are common to all the participants were that they had a close relationship with someone who had been diagnosed with cancer and that this experience took place over time. However the different types and stages of cancer and the variations in experiences of the illness trajectory also present differences which shape the individual experience – which will be addressed later.

Time took on a different quality for the participants in this study. Life was marked by a new dimension of measurement; the intervals of time dependent on anxious anticipation or relief attendant on medical appointments or treatment. This continued in Debra’s case even when her husband was well. One finding however, was how much stronger and more able to deal with the situation most people became over time. Many participants commented that they had surprised themselves with the inner strength they had discovered managing the situation as it unfolded.

The fact that the this study specifically involved the close relatives of people with cancer also represented some common features. As Stacy (1997) comments, cultures define diseases. Nearly all the participants at least initially associated the diagnosis of cancer with death. Cancer is imbued with metaphorical meaning not associated with other chronic illnesses (Flatley and Plant 1996). This even extended to the research process where it was difficult for some to even say the word cancer. Jackie perhaps typically saw it thus:

“the cancer is a living thing inside you that’s why ... it eats away your organs and it just spreads out, takes away everything .. doesn’t it.”
[Jackie 1 p.22]

Influences on the experience

The thesis is not primarily about explaining experiences but rather is designed to support a wider and deeper understanding of others’ experiences. I have stressed some of the commonalities manifest in this group of relatives but I also wish to illustrate what was behind some of the major differences of experience. There are several factors which influence the dimensions of this experience.
These influences have been addressed under four separate headings, and relate to rather different aspects of the experience. The first two which are discussed together here are external influences on the situation and in some respects are quite closely linked. Cancer features in terms of the varying physical effects which it might have on the patient and this in turn dictates in many respects how the experience changes with time. The further three main influences; the relationship with the person with cancer, life circumstances and gender (as an aspect of life circumstances) are all factors which relate to the individual.

(i) Cancer and time – the differences
The physical effect of the site of the cancer and how far the disease had progressed was obviously important in mediating this experience for the close relatives. In this study there was wide variation in the illness trajectories – lung cancer is very different from testicular cancer in this respect. The patient’s state of physical health – whether they were getting worse or better, the symptoms of the illness, or side effects of treatment for example, nausea or anorexia were also significant for those close to them, although the severity of the illness did not always translate directly into the degree of distress experienced by participants.

Time is external to the individual and unlike some aspects of life circumstances it is not possible to control, although some people did have strategies for trying to get through anxious time (to make it seem to pass more quickly). This study set out to explicitly look at the effect of the passage of time on this experience. Longitudinal studies are relatively unusual particularly when they are conducted away from the hospital. However within this small sample the individuals’ experiences were varied and uncertain.

Perceptions of the future became more complex. Elizabeth felt guilty thinking about her life after her brother’s death and Jackie and Georgina did not find it helpful when their husbands tried to prepare them for life after they had gone. Ivan’s expression that his
life was 'on hold' was probably true for several of the partners. In this study, the adult offspring were most likely to be trying to 'get on' with their life, although this was still enmeshed with their parent's illness; Betty planned to move house to accommodate her father, although she knew he might not be alive, and Jade was determined to have a family holiday, but was very anxious it would be cancelled. Furthermore, time with the person with cancer might also have a different quality, Louise for example was very conscious that she might be experiencing her mother's last Christmas.

The relatives may also lose control of 'their' time. The medical agenda of treatment and follow up would often involve the participants practically, but may not coincide with times which were easy to negotiate. There was no consultation with them about this. For example, trips to the hospital may coincide with pickup from school, or work commitments.

(ii) The relationship with the person with cancer
There are two important but separate points to make here. The first is how the relationship with the person with cancer influences the relative's experience of the illness, and secondly, how this experience influences and changes these important relationships.

The meaning of relationship with the person with cancer is fundamental to the relative's experience of the illness, and has been referred to throughout the analysis. This 'inside perspective' remains a relatively unknown quantity and generalisations should not be drawn from this sample, however it seems clear for these participants that cancer in a partner has a different meaning from cancer in a parent or sibling.

In this study the participants were recruited through the person who had cancer. Relations were thus likely to be reasonably amicable maintaining some degree of contact. The experience of those with complex or troubled relationships is therefore unrecorded. Those who had a difficult relationship with the person with cancer would
not have been asked to take part - Alison who referred herself to the study probably comes closest to representing such relationships.

The recruitment to this study had envisaged including close friends as well as family, anticipating that these people may also be closely affected by the illness. In the event only close family took part. The person with cancer universally nominated close kin (with the exception of Jack) thus illustrating that for this group the close relatives did have more significance than other relationships. Finch and Mason (1993) in a much larger study of family relationships made a similar finding; 'the extended family was alive and well and had a tangible reality in most people's lives'. This, perhaps unexpectedly, echoes the findings of several other studies in the research literature (Finch and Mason 1993).

The diagnosis of cancer however, did produce changes in the ways that those who took part in this study communicated, even between people who described themselves as very close. Bailey describes the social changes for the cancer patient, 'Illness changes us biologically, but it also changes our sense of ourselves in relation to others' (Bailey, in press). These changes were variable, sometimes planned and sometimes not considered, although the majority of the participants did reflect upon this to a certain extent during the interviews. Comparing individual's reactions and comments within the relationship felt very intrusive and was not what I had asked consent for. As Duncombe and Marsden (1993) comment, it does not seem ethically justifiable to probe in to a couple's shared secrets or to persuade one partner to voice feelings about the other that might deepen a tension within the relationship; 'A key part of emotion work where the couple's relationship is old or shaky may be the couple's management of their image to outsiders - including interviewers' (Duncombe and Marsden 1993, p.237)

The patients involved in this study were all experiencing a potentially life threatening disease (nearly a third died during the study period). Death and the fear of death are very difficult to honestly articulate and support, particularly when emotionally involved. Glaser and Strauss (1965) identified four types of 'awareness contexts' for those
approaching death and their family and professional carers: 'closed awareness', 'suspected awareness', 'mutual pretence awareness' and 'open awareness'. The cultural climate has changed in the last 35 years; the prevailing maxim being 'openness' and that it is good to talk. Only those who had actually been told their diagnosis were referred to the study and several of the relative participants said that they talked together about death. However, as Glaser and Strauss acknowledge it is difficult to describe any of the communication as completely open and, as they elaborate, 'openness does not eliminate complexity' (Glaser and Strauss 1965, p.79). Field and Copp, examining the current literature on modes of communication and patient awareness about dying, found that health workers tended to employ 'conditional' rather than 'full open disclosure' because sustaining a full 'open awareness' all the time is very difficult (Field and Copp 1999).

In this study there was an element of protection in communication, even when all were reasonably informed of the situation. The person with cancer and their close relatives were in a sense on different paths so that even in the instances of the most open communication there still seemed to be a sense of 'holding back', by the relatives, and probably also by the patients. Most participants here appeared to filter their interactions with the patient although in sometimes minimal ways. A constant full openness about the situation might be intolerable and overwhelming to live with day by day.

It is difficult to estimate how conscious these protective processes are. In some instances certainly such as with Melvin and Monica, or Jane and Jonathan the interactions might be better described as 'mutual pretence'. Glaser and Strauss imply that this requires a conscious effort. These changes in communication will all in turn invariably lead to a separateness in the illness experience, which may lead to a sense of loneliness and isolation. 'Thus, the concept of open awareness remains problematical despite its wide acceptance' (Williams et al. 1998, p.172).

(iii) Life Circumstance
The participants in this research all lived in the south east of England and were all white. It was thus not possible to make any comment about ethnic differences for families.
There was nevertheless a spectrum of urban, suburban and rural living included within the study which took place over five counties. This appeared to make little difference in terms of access to resources.

Within this group there was a wide variety of ways of living. The occupations of the participants varied from docker to dentist (information on this has been included in chapter three). Blair (1993) looked at the effect of social class differences on the experience and communication of distress. Blair used the work of Bernstein (1964) who argued that the cultural acquired speech forms act as a constraint upon social behaviour in the illness experience. Blair hypothesises that ‘the working class are relatively more preoccupied with the body as site of distress experience and the middle class respondents are relatively more preoccupied with the psyche as a site of such experience’ (Blair 1993, p.32).

The numbers in this study are too small and the backgrounds too disparate to comment with any confidence. Few of the participants in the study expressed any wish for help from professionals with talking about their feelings, but two of the most financially secure families, (the Cornwalls, and Geoffrey and Nora) particularly expressed the need to maintain a stiff upper lip. Jill (on the other hand) who lived in local authority housing, also talked about putting her head in the sand.

In this set of respondents it seems that the acquisition of information had more to do with age and personal motivation than financial resources or education. The need for information also did not appear to correspond with how affected the relatives were by the patient’s illness. The participants own feelings of vulnerability might remain as a greater barrier to attempting to obtain information than the practical difficulties, although of course this is not to discount the practical problems.

It is possible that coverage of cancer and related issue in the media may now have more impact on knowledge than social circumstances. Accounts by celebrities and others of their experiences of cancer have also probably influenced people’s perceptions of the
experience of cancer. Jackie described how she wishes her husband’s care could have been:

“I’ve seen on the television, Jimmy’s or something...... I’ve seen a consultant sitting by the bed of a woman who was going to have a cancerous tumour removed, and do you know he sat there and he did a drawing and he explained what he was going to do when he was going to do it, how she would feel”

[Jackie 2 p.26]

Spending several hours in each of the participant’s homes gave some indication of material and financial well-being. The conversations off tape at some interviews, for example with Michael and Samantha, and Anthony and Anne were focused around problems with their housing and their local environment. Samantha had brought up 6 children in a one bedroom flat and her husband could neither read nor write. This couple were currently in conflict with the council as were Anthony and Anne about the maintenance of the properties, and their interviews reflected these concerns. These couples were however both well supported by their adult children. Michael and Samantha had experienced many struggles in their life together and now did not want to be out of each other’s sight - rather like Stephen and Karen at the other end of the economic spectrum. However, what was clear was that financial resources could provide a buffer to enable people to spend time together and reduce burden of the additional worries. For example, Stephen and Andrea could afford to take time off work whereas this was much more complicated for Ivan and Elizabeth which exacerbated the situation for both of them.

The demands made by life did have an impact on these relatives, and this links with the other influences on the experience. For a partner it seemed easier to put aside other issues. For siblings and adult offspring the needs of family and work made them feel very stretched. The number of concurrent stresses which beset participants had not been anticipated, although with hindsight it should have been. For example, other illnesses and deaths in the family and in particular the participant’s own poor health were all significant.
(iv) Gender

Gender is a particular (and unchanging) aspect of life circumstances. This was a small study, with 19 women and 7 men taking part, therefore with few men interviewed it is inappropriate to make any very general comment about their experience. The most revealing gender difference apparent in this study was that the large majority of participants were women. All married patients nominated their partner, but when they were not married they universally nominated a woman. However, for those men who did take part it appears that the dimensions of the experience were not dissimilar to those of the women. For example, the levels of distress were apparently not very different between men and women. However, the influences upon these dimensions were not the same.

Gender stereotypes are deeply embedded in popular discourse (Duncombe and Marsden 1993). Caring may be considered by both service providers and carers themselves as ‘intimately related to the female role and to domestic labour’ (Atkin 1992, p.51). Duncombe and Marsden explain the ‘gender asymmetry’ in the expression of emotion that, ‘men too value and need their intimate personal relationships’ (p.235), but as a consequence of the gendered divisions of ‘emotion work’ in many relationships men may ‘devalue and be less ready to acknowledge and express their own needs at an emotional level’ (p.236). All of the participants did have some difficulty in expressing their own feelings and a couple of the men, Melvin and Geoffrey, particularly so. When considering these participants, it seems likely that these men were very deeply distressed, but their social circumstances prevented them from articulating this (and they were also both married to women who did not ‘sanction’ the expression of emotion).

Nevertheless the ideal of caring for the patient was aspired to, and successfully carried out by both men and women - but with some differences. The men tended not to be undertaking any other caring activities whereas the women, particularly the daughters and sisters (but also partners) often had an array of other people whose well-being they felt that they had to support.
The women in this particular sample were also more likely to want to take responsibility for encouraging the patient to do more to help themselves to combat the cancer, and prevent the patient from ‘getting down’. Those who sought most information tended to be the younger female participants - the adult daughters of the person with cancer. These were the participants who also sought to influence the care that was being offered and had most contact with the professionals.

Obviously when thinking about when and how relatives might be helped it would be necessary to take into account these variations in circumstances and experiences, and to respond to individuals, but the main aim of this work is to help illuminate the broad dimensions of the experiences which give rise to these needs.

**THERAPEUTIC IMPLICATIONS**

Corner (Corner 1995) writing about the scope of the cancer nurse first identifies, ‘Assisting patients and their families to adjust and adapt to life with cancer’ (my emphasis). Although greater resources have been put into ways of assisting the person with cancer to live with their disease, aiding and facilitating the relatives needs (at least while the patient is still alive) appear to have been less of a focus for research or practice development. ‘Family centred care’ is a notion which is widely subscribed to but not widely evident in this study.

By revisiting what was helpful to the relatives about the process of the research and thinking further about what relevance the findings might have for practice, this section elaborates some of the possible implications for professionals working with people with cancer and their families.

*Invisible relatives*

Since describing the relatives as invisible in the analysis I have seen this term used several times, although with different emphases. For example, ‘Ignored and invisible’ is
the title given to a recent research survey commissioned by the UK Carers National Association (Henwood 1998). This paper calls for carers to become involved in partnership and co-operation at all levels of primary and secondary care. Benner and Wrubel (1989) also write that those who provide care (they are writing particularly about nurses) 'will feel the stress of being invisible' (p.368). In the chapter in this thesis on the experience of contact with health professionals, the term 'invisible' has been used to describe aspects of the relatives interactions with the health professionals. But it is in fact far wider ranging than this. The term 'invisible relatives' describes several facets of the experience. Relatives make themselves invisible because they invariably put the patient's needs before their own, indeed they often do not see themselves as having needs. They minimise the effects of the illness. Those close to the person with cancer may remain on the margins of professional care. This marginalisation is sought by some, but others may benefit from some control over the situation and lack of information and lack of supportive structures make this more difficult.

The contact with the professionals is likely to be couched in terms of how best to fulfil the patient's needs, with the relative possibly perceiving that they have no 'right' to make any requests for themselves. The relatives may not behave in a way which is expected by others particularly health professionals who will have no knowledge of the histories and motivations of those involved. As Bailey (in press) writing about cancer, care and society comments; 'illness and illness behaviour are subject to a kind of contract, agreed between members of a community or society, which stipulates that it is okay to act in certain ways but not in others'. Health professionals will put the patient's well-being first, and this may mean excluding those people close to the patient if they are not behaving in the way they expect them to.

**Lessons from the research methods**

One of the most challenging periods during this research was the early realisation that the initial parameters for data collection did not fit with the aims of the study or with the reality (as I perceived it) in the field. New avenues of research literature alongside
debate with co-workers, colleagues and friends engendered the resulting style of data collection and analysis which was maintained throughout the course of the study.

The process of undertaking the research, for example: negotiating access, obtaining consent, debriefing, renegotiating access and most importantly my own developing relationship with the participants were integral to the analysis of the tape recorded data. The very sensitive nature of the issues being studied meant the greatest care had to be taken that the participants frequently vulnerable state of well-being was not disturbed. The social concerns or trajectory through the field work thus took precedence over the technical trajectory. The research methods used were predominantly those described by sociology and to a lesser extent anthropology. However, the fact that this study was undertaken by a cancer nurse, trained to support people with cancer, led to distinctions that were perhaps not initially fully appreciated.

The acknowledgement that the research conferred on the participants' own situation, as well as the opportunity to talk about their personal experiences, appeared to provide for many, but not all, something which they seemed to value. The reflexive nature of the data collection did allow for this influence to become part of the analysis. However I could possibly have gained more insight into the therapeutic nature of the interview process if I had been more sensitive to this earlier on. At the time I did not seem to want to acknowledge what was happening, and yet I was often aware that the stories that I was 'holding' for some of the participants made me feel very 'full'.

There are undoubtedly some similarities between the research interview and a 'therapeutic' intervention; the attentive listening, the 'holding' or 'containing' of the distress (Emmanuel 1994). However, it is problematic to view the research interview as an agent to facilitate change. Coyle and Wright (Coyle and Wright 1996) have written that that the 'use of the counselling interview to collect data on sensitive topics is a practical research method which is beneficial for both interviewers and interviewees' (see section on Benefits and drawbacks for participants, chapter three). Undoubtedly teaching the use of counselling skills, particularly in listening, is helpful to those who
are undertaking research in potentially distressing situations. But there are limits to what may be achieved by such approaches. The training, Coyle and Wright suggest, is minimal, and there is no ongoing therapeutic contract with participants. Coyle and Wright cite the benefits of 'insights' for one participant of 'reliving things' ... 'just hidden a bit'. This runs the risk of disrupting someone's coping mechanisms without any follow up to monitor the effect that this might have on an individual. Bailey (1996) however, criticises the ‘action tomorrow’ reassurances of some qualitative research', (p.72) commenting that in the future, ‘Cancer care research should seek ways of re-connecting investigation and action’ (p.68).

On reflection I can now see ways in which it may have been possible to work with and facilitate the participants to find ways of addressing some of the difficult areas of their experience, which would in turn inform the research. This might potentially have taken the form of a ‘co-operative inquiry’ (Reason 1989), or an ‘action research’ project which by entailing ‘collaborative spirals of planning, acting, observing, reflecting and replanning’, could have been more responsive to the difficulties in the participant’s experiences (Meyer 2000, p.178). However, when I started this study it was not with a view to facilitating change. I wanted to describe the experience first. Despite my nursing experience I knew little about the relatives’ life at home and would have had to build significantly on my skills and confidence to undertake this kind of research. Furthermore I would have needed a great deal more institutional structural support to work in this way, which even had I wanted to use these approaches at the time, would have been extremely difficult to achieve.

In addition, one of the reasons postulated why the participants benefited from taking part in this project was that they felt free to talk about their own difficulties because they believed that this would be helping others. They did not perceive it as any kind of ‘therapy’ which they were so wary of for themselves. Moreover, I was free to listen because I was not trying to think of solutions.
Healing power of the story

It was not easy for these relatives to talk about themselves. They invariably tended to focus their story around the experiences of the person with cancer. As Klienman (1988) comments ‘The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long term course of suffering’ (p.49). This project was explained to the relative participants as being about their experiences of illness in someone close to them, but I had interviewed the patient first. This fact may have influenced their perception that what was really important was the person with cancer. Here again, like the healthcare professionals at the hospital, my contact with them was because they knew someone with cancer - and perhaps they thought that they were responding to my agenda. However, I believe their reluctance to focus on themselves, went further than this. It is challenging to talk about oneself when the fundamental issue is the illness in someone else.

The research project did however facilitate the relatives to talk, and the participants’ own experiences of the illness did emerge - for some more clearly than for others. The interviews allowed an opportunity to fit this difficult time into their own history in terms of other painful episodes. There were several comparisons with other deaths experienced and other traumatic times were reviewed. I was at times very disturbed that the interview might be re-igniting other past losses, but although the accounts were frequently emotional the chance to place this episode into their history in conjunction with other sadnesses, may have helped to provide context - for which there may have been little other opportunity. As Nicholson (1997) comments, ‘Finding meaning is a continual process as experiences are incorporated into the existing life story. This is not easy and may require revisiting the same experience an infinite number of times’ (p.19).

Taking part in the research prompted reflection and self analysis which many participants said had not taken place, or had not felt right elsewhere. Storytelling and exchange is one of the important elements of being human. Some of these people were no longer able to fully share their thoughts and reflections with those closest to them - perhaps making them feel more alone. The relatives who took part in this study
appeared to find it hard to focus on their own experience and yet when they did so many commented on how useful this was. I had not anticipated that the participants would find this story telling so beneficial. The remarkable thing about this ‘therapeutic’ side effect of the research project is that I had done nothing, suggested nothing, given nothing - just listened very attentively.

It is hard to untangle whether the therapeutic elements of these interactions could be reproduced under other circumstances. Intense listening with a tape recorder may engender a different kind of story telling. What is certain is that acknowledging the relatives’ experience and enabling them to have a space to talk about themselves without feeling guilty was important. Smithbattle (1994), who interviewed teenage girls about their transition into motherhood says the opportunity to tell their story for the research, ‘sometimes helped them to find and respond to their own voices, legitimised their concerns, and clarified their dilemmas and difficulties, with the result that their practical understanding of the situation was sometimes deepened’ (Smithbattle 1994, p.161).

Narrative has increasingly become an area for discussion both in terms of academic and therapeutic interest. Mcleod (1997), a psychotherapist, comments, ‘If there is any common ground among narrative therapies, it lies in the intention to give the client every opportunity to tell his or her story, to really listen to these stories, and to allow space for the telling of the new or different stories’ (McLeod 1997, p. x)

The reciprocity of the research relationship may have helped to achieve this - the fact that they were doing something for me which allowed them to tell their story without feeling a burden, whereas it might otherwise have been difficult to accept. Furthermore, there was no perception that they were not ‘coping’. Conventional psychotherapy or counselling does not allow this - it is very much focused on the client and is ‘for them’. The therapist is a blank sheet. Nurses who can work in partnership with the family may be well placed to provide therapeutic listening, if the institutional and social structures of their employment would allow them to do so within a supportive environment.
Implications for practice

In a climate of stretched resources the focus of professional care has to be with the person who is sick. Indeed this is what the family themselves would want. Healthcare is largely reactive and where a problem is not immediately apparent it is less likely to be addressed. Some relatives are able to make their needs known to the professional carers but, as has been illustrated here, many are not.

Limited resources again mean that a priority for much research which has involved the relatives of the person with cancer has looked at the ways that they can be supported to take care of the patient at home (Cassileth et al. 1985; Quinn et al. 1986; Omne-Ponten et al. 1995) and on addressing the burden of care which this might create (Oberst et al. 1989; Carey et al. 1991; McCorkle et al. 1993). The focus of several research studies is to identify those who will not cope, rather than on supporting those who do (Ell et al. 1988; Kissane et al. 1994). This section here is written particularly from the perspective of nursing, but may also have implications for other health care professionals.

There is currently no agreed health related outcome measure to record the effectiveness of care for the family. Time spent with relatives may create a tension with time ‘lost’ on the more technical aspects of caring for the person with cancer - where there might be more measurable success, for example, relief of pain or administering chemotherapy. It may be unclear even to the nurse involved how productive the time spent with an individual relative might have been. Making a connection and establishing a relationship with family members may make the professional carer feel vulnerable on a number of fronts unless this is undertaken within a supportive framework. The therapeutic implications of this research require time from the health professionals which as Cribb (in press) points out, ‘is, in every sense the most valuable resource of health services and is itself necessarily rationed’. He believes that the immeasurable issues of caring which are often ‘informal and invisible’, even when undertaken by health professionals are often neglected by the influential policy makers. However, a few words, a gesture, a rearrangement of the mornings work schedule do not require a huge amount of time, and furthermore much is dependent on the priorities made for the
time available. Health professionals notoriously say that they have not got time when, although time is undoubtedly limited, it is not contracted absolutely.

Nevertheless, professionals perhaps do not have the emotional resources to spare. As authors such as Menzies Lyth (1988), Smith (1992) and Lanceley, (1997) have indicated working at an emotional level has consequences for the nurse’s self identity and, unless the work environment facilitates support, the nurse’s defences against this anxiety may cause her to withdraw. Clearly it is vital to get structural support for this element of health professionals work. Thus it is not just work time that must be allowed for, but also time must be sanctioned to allow for reflection and supervision. However, if emotional distress is increasingly recognised as a causal factor for physical disease and there is an broadening emphasis on the importance of emotional wellbeing for health, there is perhaps a potential for more resource. An editorial in the British Medical Journal, comments that those ‘who determine the allocation of NHS funds, will need to believe that emotional and social wellbeing are at least as important for health as physical wellbeing and invest both development and research funds accordingly (Stewart-Brown 1998, p.1609).

There is no neat way to describe the care that might be helpful to those close to someone diagnosed with cancer. One of the difficulties of completing this research and carrying it forward into practice is that although the relatives clearly may experience long term distress there is not a clear solution. Many authors writing about the family of people with cancer do attempt to provide an answer about what can be done to help. As McKissock (1999) comments ‘Nurses are trained to be ‘doers’, to solve problems, and as such, often struggle against the empathetic helplessness that is an essential part of a supportive role’ (McKissock 1999, p.316). Kuyper and Wester (1998) investigated the support that GPs could provide for the partners of those with chronic illness and found that in practice the GPs role was unclear and very modest, commenting that, ‘one should get their [partners] confidence and take time to listen to them’ (Kuyper and Wester 1998, p.249).
In some respects it is important to recognise that the relatives may not want our support. They may not want their private grief to be sanitised and taken away. Intervention from outsiders particularly in their home is cited by several (for example, Georgina, Samantha and Jackie) as unwelcome. Some relatives may be very difficult to identify, and there is a limit to how much chasing one could or should do. The participants in this study said that they did not want to see a person such as a counsellor - although if this had been sensitively offered to them in practice rather than in theory it might have made a difference. The relatives have been described as invisible and to a certain extent they have chosen this invisibility and have a right to preserve it. It is vital not to interfere when one really is not wanted, but ignoring the issue may be equally invalid.

The relatives’ way of managing the situation, emotionally and practically, needs to be worked with. Effective support requires careful listening and sensitive negotiation. To approach this in a less than subtle way might cause additional distress. There are it seems some common elements to their experience which prevent those close to the patient from expressing or attending to their own needs, at least until the person with cancer is dying or has died. Providing support for those close to a person with cancer undoubtedly takes time, but in terms of the health and well-being of these people it could potentially be very productive time. Thus acknowledgement is crucial even if there is no further intervention, alongside an openness and a readiness to listen to what the relative has to say in a constructive, but non-judgmental way. Lanceley (in press) describes the importance of mutuality and reciprocity within the nurse-patient relationship (which may equally be applied to those close to the patient). This involves acknowledging the person’s distress with ‘acceptance, warmth, genuineness and empathy’. Empathy is felt where the nurse listens, hears ‘understands and, most difficult of all is able to convey she understands’ (Lanceley in press).

Benner and Wrubel (1989) comment that illness can be a very isolating experience. The relatives, for all the reasons stated, are frequently more isolated in their distress than the person who is ill. Benner and Wrubel writing here about the patient illustrate how an understanding of the meaning of what is happening can be helpful;
“Even when no treatment is available and no cure is possible, understanding the meaning of the illness for the person and for that person’s life is a form of healing, in that such understanding can overcome the sense of alienation, loss of self-understanding, and loss of social integration that accompany illness.” (Benner and Wrubel, 1989, p. 9)

Klienman (1988), a physician as well as an anthropologist believes that by examining and interpreting the meaning in the individuals’ experience of the illness it would be possible to deconstruct the issues which increase distress, and thus provide more effective care. He comments;

“The work of the practitioner includes the sensitive solicitation of the patient’s and the family’s stories of the illness, the assembling of a mini-ethnography of the changing contexts of chronicity, informed negotiation with alternative lay perspectives on care.” (Klienman, 1988, p.10)

This is gaining some acceptance. A recent editorial of the British Medical Journal comments; ‘medicine seems likely to serve its patients best by incorporating into their treatment an appreciation of individual patient’s experience.’ And continues; ‘a more ‘narrative’ understanding of illness might be important diagnostically as well’ (Evans and Greaves 1999, p.1216) . Klienman, suggests an ‘empathic witnessing’ and Judd (1994) proposes the notion of being an ‘involved witness’, for the family ‘to feel, to hear, register, and attempt to contain’ (p.97). ‘Being with’ the family at the difficult times from an early stage is important to subsequent work if the individual is to feel ‘understood and believed’ (Judd, 1994). One of the important elements of the research process was to try to gain an understanding of the experience over time – perhaps this is why the bereavement interviews appeared such a natural, although initially unplanned part of the process.

If acknowledgement is made, and the relative is aware that the health professional is truly open to contact, then it will be up to the relative to a certain extent to choose how to use this availability. The difficult and often complex experience of those close to someone with cancer is not going to be ‘made better’, as Melvin illustrates:
"No, cos there’s nothing you can do, and the thing is now, I can honestly say that it’s at the back of my mind, and that’s where it’ll stay... you know..."  
[Melvin 2 p. 4]

However, Melvin did state that he and his wife did not receive enough information. The need for information is commonly highlighted by research in this area (Hinds 1985; Tringali 1986; Lewandanski and Jones 1988). Nearly all the relatives who took part in this study wanted to understand more about what was happening, but the emphasis of this from individual to individual was very different. Information is required as an ongoing process, rather than as a one off information bulletin immediately after diagnosis. Benner and Wrubel (1989) describe the nurse as ‘providing a perspective about the progress and recovery trajectory’ (p.392). The patient themself cannot be relied upon to pass on information to those close to them, and where the person with cancer is reluctant for others to know about their treatment and disease status this may require a sensitive negotiation with the patient. Del Vecchio Good and colleagues (1994) in a paper entitled ‘Oncology and narrative time’ use the term ‘therapeutic emplotment’ to describe how American oncologists address the challenge of emplotting the illness within a larger therapeutic story:

“In the treatment of cancer, emplotting the illness and the development of therapeutic stories also speak to much more profound questions: What is likely to happen? Will the treatment be successful? What will really happen next?” (Del Vecchio Good et al. 1994, p.855).

It is a delicate balance to mutually create a story for the illness. Some families do want or need a plot mapping out for them which they may then refer to - although there can never be any guarantee of certainty. Others may want to use the professionals where and how this coincides with their own personal construction of the situation, which may be complex for both professional and indeed possibly the relatives themselves to interpret.
The interviews illustrated that many do not like dependence on outsiders. The need to care has been clearly identified in many of the participants in this study, as have the difficulties of standing by and watching what the patient is going through. The compulsion to do something to improve the situation, if only just to get through it (for example by cleaning) is pressing in many. One of the starting points for this research was that it was to be about the experiences of those close to the patient themselves and not about how these individuals could best support the needs of the patient. Nevertheless, support and advice from hospital and community staff to facilitate the family in caring for the person with cancer in a way that is appropriate for them and their situation could potentially be very helpful in living with the feelings of helplessness and anxiety experienced by the participants. For those close to the person with cancer, increased knowledge of the ways in which they might support the person with cancer – even if they’re not physically ill or having treatment, may build the family’s confidence and thus promote the relatives’ own emotional and physical well being, potentially increasing feelings of control over the situation. This might represent the support and acknowledgement of what the relatives would do anyway, for example with feeding, listening and encouraging, or other more practical tasks. As this study illustrates each individual’s requirements are very different, but it may be easier for the family to allow themselves to be supported by the professionals if they believed that it would be of benefit to the person with cancer.

CONCLUDING COMMENTS

The research illustrates why the relatives’ ways of managing the illness made many of them ‘invisible’ to professional carers and marginalised from the care that the person with cancer received.

In order to provide support for those close to someone with cancer there are many practical concerns, both for the professional and for the relatives. Regardless of the individual’s social circumstances there are certain barriers (often psychological) to providing help and information for the relatives. This suggests in many respects that the
fundamental issue is to reform the ‘culture of care’, rather than being more prescriptive in areas such as information giving or breaking bad news.

This study has focussed on the experience of the individual close to someone with cancer, and perhaps its central lesson is that, faced with the potential erosion of their identity-sustaining relationships, there is a place for another individual to help by attending to their experiences and feelings – so long as such attention is freely sought and given. No system or role definition can in itself provide for this – although much thought needs to be given to how institutions and roles can be constructed to facilitate and ‘contain’ this interpersonal process.
APPENDIX
CONSULTANTS CONSENT FORM
Study: Patients’ perceptions of need and relief during the first year following a diagnosis of malignant disease

CONSULTANTS’ CONSENT FORM

Consultant.......................................................................................................................................

Patient’s Name...................................................................................................................................

Address.....................................................................................................................................................

...............................................................................................................................................................

Tel. .........................................................................................................................................................

General Practitioner.................................................................................................................................

Address.....................................................................................................................................................

...............................................................................................................................................................

Diagnosis..................................................................................................................................................

Stage .....................................................................................................................................................

Date of diagnosis.....................................................................................................................................

Date of birth ............................... Sex................................................

Has your patient any previous history of cancer?.....................

Has your patient any history of psychotic illness?....................

Is your patient English speaking?.................................................................

In terms of the diagnosis, what have you told your patient? For example "malignant disease", "malignant tumour", "cancer", "cancerous tumour", "growth" or other? (please circle/complete where appropriate)....................

I agree/ do not agree* to this patient being contacted for the above-named project - please indicate reason for excluding patient from study.

Signed.....................................................................................................................................................

Date......................................................................................................................................................

Please return this form in the reply paid envelope as soon as possible.

Many thanks for your help and consideration.
Document 2

SPECIMEN LETTER TO GENERAL PRACTITIONERS
Dear Dr

Re: Patient’s perceptions of need and relief during the first year following a diagnosis of malignant disease

The above project, which is being funded by Cancer Relief Macmillan Fund, is a study of how patients with cancer perceive their needs during the first year from the date of their diagnosis. This will involve three interviews, the first being at three months following the diagnosis, the second at five months and the third at one year after the diagnosis.

Included in the study are patients aged between 20 and 70 who have been diagnosed as having cancer of the lung and who have been informed of the diagnosis (please see enclosed summary).

I am writing to advise you that Dr Bloggs has suggested that your patient, Mrs Smith, 22 Downside Road, Biggleswick, may be suitable for this project if you agree.

I enclose a copy of the letter we propose sending Mrs Smith. The purpose of this letter is to introduce the researcher to the patient. The nature of the enquiry will be explained to the patients during the first interview, once they have acknowledged their diagnosis to the researcher. This procedure is to ensure that patients who are not clearly aware of their diagnosis are not caused unnecessary distress by a letter which refers to a study about malignant disease.

Unless I hear to the contrary within the next two weeks I will assume that you are happy for me to make contact with her.

Yours sincerely,

Hilary Plant
Researcher
Document 3

SPECIMEN LETTER TO PATIENT
Dear Mrs Smith

The Centre for Educational Studies of King's College London is undertaking research into the sort of help people feel they need when they have been in hospital. Dr Blank has suggested that you may be willing to participate in this project and your family doctor has not raised any objections.

I would first like to discuss our study with you in more detail and I will therefore telephone you within the next week or so to see if you would be willing to meet me, either at your home or at an alternative place convenient to you. If there is any difficulty about this please feel free to ring me at King's College (071 872 3161) between 10.30 and 3 p.m.

I do hope you will feel able to help us,

Yours sincerely,

Hilary Plant
Researcher
Document 4

CHECKLIST FOR GAINING ACCESS TO PARTICIPANTS
GAINING ACCESS TO PARTICIPANTS

1. Did the patient mention during the interview any difficulties that their loved ones may be experiencing?

2. Was the relative study mentioned before the end of the patient interview?

3. Was the closest relative or friend easily identifiable during the patient interview? If not, how were they identified?

4. What was the patients' response to the request to interview their relative?

5. How willing were they to consent to the relative being interviewed?
6. If consent was not given then why not?

........................................................................................................................................
........................................................................................................................................

7. Method of contacting relative.

A) face to face. B) telephone. C) letter.

Comments and dates contacts made.
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8. Response by relative to request for interview?

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........................................................................................................................................

9. Arrangement made?

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........................................................................................................................................
........................................................................................................................................

10. How do you feel about this?

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........................................................................................................................................
Document 5

POST INTERVIEW QUESTIONNAIRE
POST-INTERVIEW QUESTIONNAIRE

AGE..................................  SEX..................

RELATIONSHIP TO PATIENT (& FOR HOW LONG)

MARITAL STATUS..............................................................

FAMILY STATUS..............................................................

OCCUPATION..............................................................

General health

EATING (pattern changed, lost weight)

SLEEPING (pattern changed)

GENERAL WELL BEING (been to Dr more frequently about own health)

Help and Support

1) Are you receiving any sort of practical help at the moment (i.e. financial, household, transport etc.?) ..............................................................

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.....................................................................................
2) Can you think of any sort of practical help that you would like to receive? ..............................................................

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3) Is there anyone in particular who you feel is providing you with (emotional) support at the moment? ..............................................................

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4) If you would like some help in this way, who would you most like to provide it? ..............................................................

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5) Have you had contact with any of the following?
Doctor (hospital) ..........................................................
Sort of contact ......................................................
Were you happy with that? ........................................

Doctor (home) ..........................................................
Sort of contact ......................................................
Were you happy with that? ........................................

Nurse (hospital) ......................................................
Sort of contact..............................................
Were you happy with that?..................................

Nurse (home)................................................
Sort of contact.............................................
Were you happy with that?..................................

Home help..................................................
Sort of contact.............................................
Were you happy with that?..................................

Social worker..............................................
Sort of contact.............................................
Were you happy with that?..................................

Voluntary worker...........................................
Sort of contact.............................................
Were you happy with that?..................................

Spiritual leader..........................................  
Sort of contact.............................................
Were you happy with that?..................................

6) Have you had help from any of the following?
Relative....................................................
Sort of help..................................................
Were you happy with that?..................................

Friend......................................................
Sort of help..................................................
Were you happy with that?..................................
Neighbour..................................................
Sort of help..............................................
Were you happy with that?..............................

7) Have you sought/had any other sort of help?
Support group..........................................  
Are you aware of service?.............................

Telephone helpline.....................................
Are you aware of service?.............................

Books or leaflets......................................
Are you aware of any books or leaflets?..........

Other organisations.................................
Are you aware of any other organisations?.......  

8) Is there anything else that you have found useful at this time?
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9) What was your reaction to being asked to take part in this study?
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........................................................................
10) Having completed the interview, I am interested in hearing about how you are now feeling. For instance we have been going over some of the things that have happened during the last few months and this may have been difficult for you. So perhaps you could tell me a little bit about what you thought about the interview.
Document 6

POST INTERVIEW COMMENTARY
Ref...................

Post-interview commentary

1. Was participant alone during the interview?

2. Were there any interruptions?

3. Did you meet any other members of the family and if so who?

4. How willing was participant to be interviewed?

5. What was the emotional state of participant during most of interview?

6. Were there any problems?

7. How easy was it for participant to tell their story?

8. Comment on the debriefing phase of the interview
Difficult questions.

11. What were the issues the participant found it difficult to talk about?

12. Do you feel good about this interview? What could have improved it?

13. How do you think that the participant felt after the interview?

14. How do you think that the participant perceived your role during the visit?

15. Did you give any advice?

16. Had patient discussed their interview with the participant?
17. Time and place of interview

Day of week:

Time:

Place of interview:

How long did visit take in total?
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