

## Chapter 4

### Research Design and Method

#### Introduction

As discussed in Chapter One, previous research on anticipatory grief has been based on the assumption that the phenomenon exists (e.g., Clayton et al. 1973; Kastenbaum & Costa 1977; Rando 1986a). That is, it was taken for granted that anticipatory grief was an intrinsic component of confronting an impending loss. Assuming the existence of a fixed reality about the concept has meant that the research has focussed on attempts at discovering facts about the phenomenon, for example, whether experiencing the effects of anticipatory grief are benign, harmless or deleterious. The methodological concerns of these quantitative studies have focussed on counting, measuring or attempting to reveal causal relationships between anticipatory grief and other social phenomena. Furthermore, data have been analysed through numerical comparisons and probability inferences and reported through statistical analyses. Sweeting and Gilhooly (1990) suggest that there is a need to develop the operational concept before attempting to investigate its impact. This call for further exploratory research arises from a number of problems associated with previous empirical work. These include the accumulation of inconsistent information concerning the effects of anticipatory grief (Rando 1986a), the limited conceptual and empirical underpinnings of the concept (Siegel & Weinstein 1983) and the argument that it is a socially constructed phenomenon (Fulton et al. 1996). To understand the experience of individuals confronted with the expectation that they will encounter a significant loss, it is necessary that research be conducted during the period in which the 'syndrome' is thought to occur, that is, prior to the anticipated loss.

The purpose of this chapter is to present the research design and method chosen to investigate the experiences of individuals living with the life-threatening illnesses of cancer and HIV/AIDS and clarify the concept of anticipatory grief. The chapter begins with the rationale for focusing on the life-threatening diseases of cancer and HIV/AIDS followed by a description of the study design, sample size and composition, profile of the informants, sample selection and the location and conduct of interviews. The chapter also discusses

how the researcher's changing knowledge and experience with the topic and the problems experienced with recruitment of prospective participants influenced the project's evolution from its original design. Limitations of the study, resulting from decisions taken concerning methodology, are discussed as appropriate throughout the chapter. The chapter concludes with a discussion of data analysis.

### **Rationale for selecting cancer and HIV/AIDS**

Two factors are crucial in the development of a study aimed at re-examination of the concept of anticipatory grief. Firstly, identification of a situation in which individuals are confronted with the expectation that they will encounter a significant loss. That is, identifying a situation in which individuals have a reasonably based expectation that a significant loss will occur. Secondly, that the loss be expected within a reasonable time frame. Specifically, the loss should not be expected within a matter of days, as in a sudden, serious illness or accident, or at some indefinite period, such as with a degenerative disease (e.g., multiple sclerosis, motor neurone disease, heart or kidney disease). The later stages of life-threatening diseases of cancer and HIV/AIDS meet these criteria. The selection of these two diseases resided not only in their life-threatening aspect, but also because they have some similarities and differences that may influence individuals' responses to the subsequent illness experience and the period during which a significant loss is expected.

The major similarity between these two diseases is that both are prominent and have considerable symbolic representation within the broader community. As the two most powerful illnesses, in terms of symbolism, they are encumbered by the trappings of metaphor (Sontag 1991) and metaphors, like concepts, models and analogies provide the spaces for making new statements within any specific discourse (Henriques, Holloway, Urwin, Venn & Walkerdine 1984). Furthermore, the discourses of both diseases are in a complex interrelationship, not only with the discourse of grief, but also the other, previously identified, discourses that are likely to influence individuals' perception and thoughts about the future.

A number of differences between cancer and HIV/AIDS as life-threatening diseases, that may influence individuals' illness experience, are evident prior to the development of any research project. Firstly, the length of time the community has been exposed to each

disease. For example, cancer has a long history of knowledge development. Consequently, the common sense discourse of cancer is well established, as is the corresponding medical discourse, and expectations of how individuals should react, are entrenched within these discourses. Alternatively, HIV/AIDS is a phenomenon of the late 1970s and early 1980s and, initially, there has been limited time to develop established expectations about how individuals should react. Furthermore, there were fewer differences between the common sense and medical discourses.

Secondly, there are differences in the amount and type of knowledge concerning the cause of each disease. The cause of HIV/AIDS is known. Within a relatively short time from the introduction of this new disease medical science had proved beyond question that a virus is responsible for the development of HIV/AIDS. The virus irreversibly damages the immune system to the point where it can no longer successfully defend the body against other organisms. It is these other, opportunistic, infections that ultimately lead to the individual's death. Furthermore, the method of HIV infection is known: infection results from the transference of infected body fluid from one person to another. However, knowledge concerning the cause of cancer is not so definitive. Although some carcinogenic substances have been identified by medical science, the actual causes of cancer are not yet fully understood. Furthermore, there is considerable speculation surrounding the factors which may predispose some individuals to develop cancer (Lowenthal 1996). The significance of this difference resides in how this aspect of knowledge influences the definition of each disease as a social object and individuals' subsequent interaction with this social object and their own diagnosis. The certainty surrounding the causal aspect of HIV/AIDS is not likely to lead infected individuals to question what caused their infection. However, the uncertainty surrounding the causes of cancer, and the diversity of associated beliefs within the common sense discourse of cancer, is likely to influence individuals' reaction to personal diagnosis.

Thirdly, differences exist concerning the outcome of each disease. Currently, there is no known cure for HIV/AIDS. That is, there is no medical knowledge available concerning how to eradicate the virus from an infected individual's body. However, although the idea that cancer is a death sentence is so firmly rooted in the common sense discourse, medical science has achieved a situation in which cancer "... cures are regularly achieved"

(Lowenthal 1996, p. 3). This difference is likely to influence how individuals react to their diagnosis. Individuals diagnosed with cancer are more likely to be influenced by the discourse of hope than their HIV/AIDS counterparts.

Fourthly, there is a difference in the incidence of each disease. The incidence of HIV/AIDS in Australia is prominent within a relatively small, but well established community, the gay community (Commonwealth Department of Health and Community Services 1996), whereas cancer occurs across the wider community. The significance of this difference is that those who are infected with the HIV are likely to have more personal contact with the disease than their cancer counterparts have with cancer. For example, gay individuals diagnosed as HIV-positive are likely to have a number of friends who have either already died as a result of the virus, or are experiencing the effects of opportunistic infections (Cherney & Verhey 1996; Kelly & Raphael 1992; Klein & Fletcher 1987; Nord 1996). In addition, the gay male community had already developed a wide variety of social, cultural and political institutions which were relatively cohesive and were rapidly mobilised for involvement in HIV/AIDS-related policy decision making and education campaigns (Altman 1992b; Dowsett 1992; Padgug 1987). For example, the Australian gay press had been concerned about gay men's sexual health since the late 1970s and almost exclusively reported the earliest news stories of the emerging disease until 1983-84 when patchy, and frequently sensational, coverage began to appear in the mainstream media (Dowsett, 1992).

In contrast, individuals with cancer do not have the same personal familiarity with the disease as do their HIV/AIDS counterparts. Although individuals diagnosed with cancer might 'know' someone else who has had cancer, the relationship is likely to be more distant (e.g., parent, extended family member, or acquaintance). That is, individuals diagnosed with cancer are less likely to have lived through the experience of a number of their peers or close friends developing cancer. Consequently, their knowledge of cancer prior to their own diagnosis is more likely to be influenced by the common sense discourse of cancer.

Finally, there is a difference in the stigma associated with each disease. Individuals diagnosed with cancer are stigmatised as a result of the common sense discourse belief that cancer is contagious and the individual is culpable for the development of their disease but not for their lifestyle. However, considerable stigma has been ascribed to HIV/AIDS

because of its initial close association with socially stigmatised groups (e.g., homosexuals, intravenous drug users, and prostitutes). Consequently, cancer appears to be a more socially acceptable disease than HIV/AIDS. This is likely to influence how individuals react to their own diagnosis and illness experiences.

## **Research design**

The current research was designed as a cross-sectional study using a combination of qualitative and quantitative methods during a two part interview. The selection criteria for inclusion in the study were that prospective informants have:

1. a diagnosis of seroconversion or an AIDS related condition (ARC); or
2. a diagnosis of life-threatening cancer.

In addition the informants had to:

1. be well enough to participate in the research; and,
2. have sufficient command of English to engage in an interview.

Part A of the interview consisted of an unstructured interview to obtain, in their own words, individual's story of their experiences of living with a life-threatening illness. The duration of interviews ranged from 1 to 3 hours and was audio-taped for the following reasons:

1. Content analysis of qualitative data depends on the accuracy of the data collected and taping enables the researcher to collect precise data.
2. Taping is less intrusive and a more effective method of collecting qualitative data than note taking during the interview.
3. Taping each interview allows the researcher to concentrate on the issues that arise during the interview rather than be distracted while note taking.

After completing Part A informants completed Part B, a structured questionnaire, consisting of the following well established, instruments:

1. The State-Trait Anxiety Inventory (STAI) (Spielberger, Gorsuch, Lushene, Vagg & Jacobs 1983);
2. The Collett-Lester Fear of Death Scale, (FODS) (Lester 1990);
3. Social Readjustment Rating Scale, (SRRS) (Holmes & Rahe 1967);
4. The Rotter Internal-external Locus of control, (Rotter 1966); and,

The above instruments were selected in lieu of a specific grief inventory as they were considered to provide more appropriate data for the study of the experience of living with a life-threatening illness and the available grief inventories are heavily biased toward death as the trigger for the grief being measured.

### **Sample size and composition**

A number of difficulties (detailed below) were encountered in recruiting prospective participants which resulted in the selection of a 'convenience' sample of eighteen informants. The sample is labelled as convenience because the researcher was forced to include whoever agreed to participate rather than following established sampling techniques. It is acknowledged that problems with the final sample do not allow for generalisation of study conclusions to the wider population. However, a number of issues are raised that indicate further, more broadly based, research is warranted (see Chapter Ten).

The interviews were conducted during the period March 1992 to February 1994. Individuals were interviewed as they became available and no attempt was made to conduct block interviews. That is, no attempt was made to interview all individuals diagnosed with one disease prior to commencing interviews with individuals diagnosed with the other disease. The distribution by illness and gender are provided in Table 4.1.

The nine individuals diagnosed with a life-threatening forms of cancer were interviewed between March 1992 and February 1994. The types of cancer diagnosed were cancer of the clitoris (2), cancer of the cervix (3), cancer of the ovaries (2), bone cancer (1) and cancer of oesophagus and lungs (1 male). All the female informants in the cancer sample were being treated as an outpatient, or in the oncology ward, of a major hospital located in the capital city of an Australian State. The lone male informant in the cancer sample was being treated in another major metropolitan hospital within the same capital city. Since being interviewed three informants have died as a result of their cancer.

The nine informants included in the HIV/AIDS sample were interviewed between March 1992 and August 1993. All had been interviewed in an unrelated research project and, in

view of the different focus of each project, agreed to participate in the current study. One informant became upset a short time into the interview and declined to continue his participation in the project. At the time of interview, one informant had developed Kaposi's Sarcoma, one informant had experienced a series of hospitalisations as a result of opportunistic infections, a further two individuals had severely reduced T-cell counts and four informants had not experienced continuing problems after initial infection. Four of these informants have died since being interviewed.

**Table 4.1 Cancer and HIV/AIDS Sample by Sex**

Illness	Female	Male	Total
Cancer	8	1	9
HIV/AIDS	0	9	9
Total	8	10	18

### **Gender bias**

A major aim of the study was to allow individuals to identify issues they considered important during their experience of living with a life-threatening illness rather than examining researcher imposed assumptions and issues. Consequently, specific issues such as gender were not intentionally included as a special topic within the interviews. It was anticipated that with similar numbers of females and males included in the sample, these issues would be identified from the narratives. However, efforts made to increase the number of males with cancer proved fruitless as appropriate health care institutions and agencies either denied initial access or obstructed access by claiming none of their patients met the study criteria. Similarly, vigorous efforts were made to recruit female informants living with HIV/AIDS but since the numbers available were generally considered to be very small and another, Government funded, major research project had just commenced with the women's groups approached, each group declined to participate in this project. Approaches to general practitioners known to be treating female patients with HIV/AIDS also proved unsuccessful. It is acknowledged that the gender bias in the final sample precludes generalisations of study conclusions to the general population. However, a number of other issues are identified that warrant further investigation, along with the issue of gender, in future studies.

### Profile of informants

The age distribution was different for each sample; the HIV/AIDS sample, with ages ranging from the 25-29 years age group to the 45-49 years age group, was younger than the cancer sample, in which ages ranged from the 20-24 years age group to the 65-69 years age group. The age groups by marital status are provided in Table 4.2.

**Table 4.2 Cancer and HIV/AIDS Samples - Age Groups by Marital Status**

Age group	Cancer		HIV/AIDS		
	Married	Divorced	Married <sup>1</sup>	Gay <sup>2</sup>	Single
20-24 years	1				
25-29 years				2	1
30-34 years				1	
35-39 years	2			1	
40-44 years				2	1
45-49 years	1	1	1		
50-54 years	1	1			
55-59 years					
60-64 years		1			
65-69 years	1				
<b>Total</b>	<b>6</b>	<b>3</b>	<b>1</b>	<b>6</b>	<b>2</b>

Notes: 1. Refers to informant living in heterosexual relationship  
2. Refers to cohabiting relationship

Only one of the cancer informants was working in a part time capacity. The remainder were no longer in the workforce. In contrast, only one informant in the HIV/AIDS sample was not working; he was in receipt of a pension because of inability to work on health grounds. Five informants in the HIV/AIDS sample were continuing to work full-time and the remaining three informants were working part-time.



The samples also differed on length of time since diagnosis (see Profiles of informants, Appendix A). Seven of the HIV/AIDS sample were diagnosed during the first five years of the disease in Australia and, therefore, had been living with knowledge of their HIV status for between six to nine years. Of the remaining two informants one was diagnosed eighteen months, the other, three months prior to interview. The situation was reversed in the cancer sample with two informants living with cancer for long periods of time; one informant for twenty eight years, and the other for seven years. Of the remaining seven cancer informants one had been living with cancer for more than two years and three informants, less than two years (the most recent diagnosis of cancer was one month prior to interview).

### **Sample selection**

The researcher's prior experience in completing research with individuals with cancer led to the belief that prospective informants would not have difficulties with either the interview or the questionnaire. However, it was recognised that the health status of prospective participants might preclude otherwise appropriate informants. For example, some individuals who initially agreed to participate may be forced to postpone or cancel scheduled interviews because of deteriorating health. Other participants may initially agree to participate, begin the interview, unexpectedly become too upset to continue and decide to decline further participation.

The decision to seek volunteers for the study, rather than making direct approaches to prospective informants, was based on two major concerns of agencies and organisations providing services to people living with each life-threatening illness. Firstly, the frequently expressed concern regarding the sensitive nature of research about dying and death. The primary concern is the possibility of the research topic increasing stress and anxiety for their clients. Secondly, calling for informants' voluntary participation does not place pressure on individuals to participate. Consequently, agencies and organisations providing services to people living with either HIV/AIDS or life-threatening cancer were requested to provide a Letter of Invitation (Appendix B) to prospective informants. If individuals wanted to participate in the study, or were interested in obtaining further information, they were asked to make direct contact with the researcher.

It is acknowledged that this sampling technique leads to selection of a biased sample which, in turn, affects the generalisation of conclusions drawn from the study. This bias stems from the fact that individuals who volunteer their participation in research projects may have significantly different experiences than those who choose not to participate. For example, those who volunteer may be more prepared to discuss emotional issues than those who decline the invitation. Furthermore, they may have significantly different perspectives about the issues associated with their illness experience and different ways of interpreting their subsequent interactions.

Initial telephone contact was made with the directors of agencies and organisations providing services to individuals living with cancer or HIV/AIDS (e.g., hospices, support groups, oncology wards, nursing services) to briefly introduce the study and the researcher. This contact was followed by forwarding written background material (see Appendix C) outlining the rationale and methodology for the study and requesting further face-to-face discussions to clarify any concerns or issues arising from the written material.

Of the fourteen written approaches to agencies, five declined outright with reasons given ranging from 'other research already being done with patients', 'no facilities available for research' (despite none being asked for) and 'the Executive believe that patients should not be burdened by such interviews'. Five other agencies participated in formal discussions with the researcher, requested further details in writing be provided to their Ethics or Research Committee who then declined involvement for similar reasons to those above and 'there is no immediate benefit for the patient'. Of the four proposals that were approved by Ethics and Research Committees only one resulted in gaining access to informants - all females with a diagnosis of life-threatening cancer. Approval from this Ethics and Research committee of a major metropolitan hospital was conditional upon the Oncology Social Worker pre-selecting prospective informants, checking that they were prepared to participate, and, on their agreement, passing names and contact numbers to the researcher. The hospital Research and Ethics Committee stipulated that the prepared form of disclosure and informed consent (Appendix D1) be amended (Appendix D2) for use with patients from the hospital. The lone male cancer informant resulted from the researcher's personal friendship network.

No HIV/AIDS informants were obtained from formal approaches to relevant agencies, organisations or support groups. All informants in the HIV/AIDS sample were recruited via a separate research project: an ethnographic study providing a descriptive account of how individuals lived with HIV/AIDS (see Minichiello 1992). Initial agreement to participate in the present project was obtained by the other researcher. Names and contact numbers of those volunteering for the current study were passed to the current researcher.

### **Location and conduct of interviews**

Prospective informants were first contacted by telephone to introduce the present researcher and provide details of the study. Informants were given the option of having the interview at their own home, at a secure office within the university, or a confidential area within the hospital. These options were made available to encourage a greater sense of control for participants and facilitate a more comfortable environment where they had greater freedom to discuss health care and personal issues. At this initial contact, the issue of audio recording of the interviews was raised with informants. Once verbal agreement was given a mutually convenient time and place of interview was arranged. Fifteen interviews were conducted in the informant's home, two informants from the cancer sample were interviewed in a confidential area within the hospital and one informant from the HIV/AIDS sample chose to be interviewed in the researcher's home on his way home from work.

At the start of each interview the researcher again briefly discussed the study and clarified any issues that may have arisen for the informant. The issue of audio taping the interview was again clarified with the informant. The researcher also explained the need for the completion of a form of disclosure and informed consent and the informant was advised that they could withdraw from involvement with the study at any time. While the informant read through the form of disclosure and informed consent, the researcher set up the audio tape recorder so that it was as inconspicuous as possible but still visible to allow the researcher to monitor it without having undue fuss or disruption to the interview. During this period the researcher took the opportunity to continue developing rapport with the informant by identifying an unusual or interesting aspect of the informant's environment and making a genuine compliment.

The interviews for the cancer sample began by the researcher expressing interest in hearing the informant's story, in their own words, from the time of diagnosis up to the present time. The researcher sought clarification of statements made by the informant as appropriate and, by recognising the informant's need to move away from highly emotional issues at times allowed the informant to move off at apparent tangents. The researcher returned to these sensitive issues at a later stage in the interview and almost invariably the informant spoke about the issue at greater depth. The researcher was vigilant in his attempts to pick up, and check the meaning of, verbal and non-verbal cues given by the informant.

The HIV/AIDS interviews were conducted slightly differently in that the researcher had access to the transcripts of interviews conducted for the previous research. Although data from these transcripts were not analysed for the current research it was used as background information for the current research. It enabled the current researcher to clarify issues previously raised or lead into issues in a way that did not require duplication.

All interviews closed with the researcher very briefly summarising the main points of the interview and asking whether there were any other issues that the informant thought were important for the researcher's understanding of their experiences.

It is acknowledged that the narratives resulting from these interviews are not simply each informant's story but, inevitably, are a co-authored narrative. Both the informant and the researcher influence the content and interpretation of the story being told. The researcher's influence resides in the issues, comments, signs and objects chosen to be acknowledged or explored. Further bias is introduced in the form of the researcher's interpretation and analysis of these issues. However, at all times during interviews the researcher had in the back of his mind a number of issues. Firstly, Polkinghorne's (1988) application of discourse theory in gaining an understanding of the dynamics involved in the production of narratives in the interview context. According to Polkinghorne, the interviewee is the teller of the story and the interviewer is the hearer. In the interview context, the story selected to be told can function to present a particular image of the teller. Similarly, the kind of interview the hearer undertakes can affect the kind of story told. This frequently occurred during interviews. Informants often initially told their story in terms that presented them in a positive image. However, as interviews progressed and informants became aware,

through interaction with the researcher, that he was not making judgments about their actions and was really interested in their story, they began to disclose more details about their intimate responses. For example, one informant from the cancer sample initially spoke of her assertiveness during the diagnostic process. It was not until much later in the interview that this informant returned to the initial diagnostic process and, in discussing her fears about cancer and how that stopped her from seeking a second opinion, provided a very different story.

Secondly, Mishler's (1986) comment that narratives are context sensitive, both in their telling and in the meaning they give events, and their form and content are responsive to the aims and conditions of the interview situation. Thirdly, Paget's (1983) suggestion that establishing solidarity between interviewer and interviewee, and a context in which participants are engaged in trying to understand important aspects of their lives, is crucial in building a context in which the interviewee feels less need to tell stories that are primarily designed to present the self in socially valued images. The method Paget suggests to encourage the production of this type of story is asking searching and open-ended questions and supporting extended responses. This process is facilitated by using the basic counselling techniques of empathy, respect, warmth, positive regard, summarising, paraphrasing and reflecting feelings. Being non-judgmental is crucial in developing an environment of safety and trust for informants. Such responses from the researcher encouraged informants to openly discuss the more intimate details of their story. The appropriate use of these skills also demonstrates the interviewer's willingness and interest in hearing the unique meaning individuals ascribe to situations, events and experiences rather than the socially valued images and meanings. During these in-depth interviews the researcher used his years of experience and skills as a counsellor to clarify and understand the informant's perspective and, as much as possible, endeavoured to be aware of when he might be imposing his beliefs or perceptions on the unfolding of the informants' narrative. This issue was reinforced for the researcher during the pilot interviews.

### **Evolution of the research**

It was originally intended to use the combination of qualitative and quantitative methods during a two part interview with couples who have been in a relationship of at least twelve months duration and in which one partner met the following criteria.

1. GROUP 1 - an individual who has received a diagnosis of terminal cancer or terminal AIDS related condition (ARC) within 2-4 months prior to interview. Twenty couples meeting this criterion, for each illness, were to be interviewed.
2. GROUP 2 - an individual who has an approximate diagnosis of a 2-4 month period prior to death. Twenty couples meeting this criterion, for each illness, were to be interviewed.
3. GROUP 3 - the surviving member of GROUP 2, approximately 2-4 months after the death of their partner.

It was anticipated that a total of 200 interviews would be conducted, with 100 interviews relating to HIV/AIDS and 100 interviews relating to cancer. Within each of the cancer and HIV/AIDS sample 40 interviews would be with individuals diagnosed with the illness and 60 interviews would be with their partners. It was anticipated that this would overcome the principal methodological problems with prior anticipatory grief research as data would be collected on those facing their own imminent death and those facing the imminent death of a partner. It would also provide data on the experience of the surviving partner's emotions both during the period anticipatory grief is claimed to occur and after the death. A comparison of pre- and post-death experiences for one group could then be conducted.

A longitudinal study was originally considered. This would have allowed for interviewing the same informants across the three time periods, thus enabling a comparison of grief experiences for each individual and couple. However, for both diseases, the time line from diagnosis to death is often measured in years. Furthermore, the time frame for completion of the thesis restricts time available for data collection. Consequently, it was decided to undertake a cross-sectional study and use the above three groups to provide data on the experience of grief, changes experienced and identification of other important issues raised. It was also considered that Group 2 could provide data on recalled experiences associated with diagnosis and, similarly, Group 3 could provide recalled data on issues and experiences relating to diagnosis and just prior to death of their partner.

Part A of the interview was to consist of a focussed interview to:

1. Obtain the individual's story of their experiences of living with a life-threatening illness, in their own words, and;

2. Investigate the relevance of a number of issues in clarifying the grief experience during the period of anticipating a death. These issues had been identified by the researcher during his professional experience as a grief counsellor.

It was anticipated that the interview would be of one to two hours duration and that they would be recorded using audio-tapes. It was planned that while one individual was participating in this interview their partner would be complete Part B.

### **Issues influencing the evolution of the research**

Two major issues influenced the evolution of the research project namely, development of the researcher's knowledge and understanding of the topic under investigation and unforeseen difficulties associated with recruitment of prospective informants. The difficulties in recruiting sufficient numbers for the original study involved the inability to overcome the influence of inaccessible gatekeepers within the organisations approached.

#### **Development of researcher's knowledge**

During pilot testing of the interview guide the researcher became aware of the importance of Bowers' (1987) comment concerning identifying where researchers have incorporated assumptions that are inconsistent with the individual's subjective reality. The researcher became aware of how his frame of reference was inadvertently influencing the type of data collected and how, ultimately, this would affect the results and conclusions drawn from the study. Also, it became apparent during preliminary analysis of the pilot interviews that there was a difference between the way individuals talked about the disease, and their subsequent illness experience, and how members of the community talk about, and make meaning of, both cancer and HIV/AIDS. It also became apparent that this difference may, in some way, contribute to the inconclusive findings of previous research on anticipatory grief. That is, the professional discourse of anticipatory grief may differ from the discourse developed and used by individuals living with the experience of a life-threatening illness.

The original interview guide (Appendix E) was developed based on the researcher's understanding of issues that appeared to be important in comprehending individuals' experience of living with cancer or HIV/AIDS. The original version of the interview guide was divided into six topics for discussion that began with generalised issues and followed by increasingly more emotive issues. These topics were a personal story prompt, awareness

contexts, important changes and issues, social construction of illness, locus of control, and support networks. Each topic contained specific introductory questions followed by a list of issues that were considered important to explore during the resultant discussion. For example, the topic on awareness contexts was to be opened by the interviewer asking the question “Tell me about what you know about cancer/HIV/AIDS”. The issues for coverage during the resultant discussion were, diagnosis, prognosis, treatment, and progress of the illness. After two pilot interviews this format was considered inappropriate for the following reasons: the three page format was far too detailed and cumbersome to act as an informal prompt for the interviewer and it severely restricted the flow of discussion. The interviews in which this guide was used were stilted and disjointed.

Major revisions were made to the interview guide in an effort to make it a more manageable, one page format. The main topics for discussion were retained. However, the specific introductory questions for each topic were discarded as they proved to interrupt the flow of informants’ narratives. Single word or simple phrase reminders were substituted, to remind the interviewer of the issues to be covered in the interviews. The revised interview guide (Appendix F) was used during the next two pilot interviews. Although this second version was considerably less structured it was still too detailed and cumbersome and was a hindrance during interviews. More importantly, it also became apparent during the pilot interviews that the interview guide included topics that were not particularly relevant for informants’ perception of their experiences. This was demonstrated in informants’ responses to the interviewer’s questions; individuals ‘contextualised’ their response. That is, prior to responding to the actual question, informants provided background information they considered important for the interviewer in developing an accurate understanding of their experience or interaction. For example, when asked to talk about his marriage breakup one informant in the HIV/AIDS sample provided brief information about how his wife was “... the second relationship I’d ever had” and that when they married he had been “... too young and too ignorant to consider my sexuality”. He then provided detailed information on what he perceived as the trigger (disclosure of a clandestine homosexual experience) that led to the eventual breakdown of his marriage. Similarly, an informant in the cancer sample, when asked what it was like when she was first diagnosed responded with details about her diabetic condition and how, in the routine of controlling side effects of diabetes, she discovered a lump. She contextualised her behaviour by providing more background



material about the experience, and knowledge gained during the discovery, investigation and outcome of a previous lump, before responding with information about how she was affected by this second discovery. Again, this informant considered it necessary that this detailed background material be supplied prior to the information sought by the interviewer as set 'set the scene' for the informant's response to the current discovery of an unusual lump and the diagnosis..

In a preliminary analysis of these interviews it appears that this process of contextualising initial responses is important for two reasons. Firstly, it provides data on what informants consider influential knowledge that informs their decision making process. That is, it provides reasons for individuals' action. For example, the cancer informant's response to discovery of the second lump was dependent on interaction she had with her doctor concerning her first discovery of a suspicious lump twelve months earlier. Secondly, the process of contextualising these response gives informants the opportunity to 'test' the interviewer's openness to hearing information that might be considered too intimate or 'shocking' in the context of discussion between strangers. For example, the informant in the HIV/AIDS sample provides details of his first homosexual experience and his responses. There is little doubt that this was done in an effort to assess how the interviewer might respond to other, more intimate information.

The above experiences, during piloting of the interview guide, demonstrate that, despite concerted efforts to the contrary during project development, the interview guide incorporated assumptions that were inconsistent with the subjective reality of individuals living with cancer and HIV/AIDS. As the principle aim of the study is to capture individuals' meanings, definitions and descriptions of the events that occurred during the experience of living with a life-threatening illness, and understand why these were important, it was decided to discard any form of interview guide and conduct in-depth interviews in the main study. Using in-depth interviewing enables the retrieval of the informant's world by understanding their perspective in language that is natural to them. This reduces the possible distorting effect of symbols and language which may not be part of their daily usage (Minichiello, Aroni, Timewell & Alexander 1990). In-depth interviewing also allows the researcher to clarify comments made, and terms used, by informants at the time of data collection. Consequently, for the main study it was decided to

simply ask informants to tell their 'story' about their experiences of living with cancer or HIV/AIDS.

### **Recruitment of prospective informants**

Recruitment of prospective informants proved to be a major difficulty in conducting the study. This arose in two forms namely, gaining approval from Ethics and Research Committees and, having gained appropriate approval, eliciting co-operation from inaccessible gatekeepers within the organisations or agencies providing services to individuals living with a life-threatening form of cancer or HIV/AIDS.

The principle problem encountered with Ethics and Research Committees was members' inadequate knowledge of social research principles and practices, in particular qualitative methodology (Fulton 1993). Discussion with committee members often became bogged down in quantitative research design principles rather than qualitative issues. For example, the lay member of one Ethics Committee demonstrated a lack of understanding of research principles by insisting that even if a patient did not want to have the interview recorded they should be interviewed as they may simply want to talk to someone about their problems. The researcher responded with a number of reasons why this was not appropriate in qualitative research. Firstly, that the boundaries between the roles of researcher and counsellor needed to be kept clearly defined. Secondly, the interview needed to be audio-taped to ensure accuracy of data. Thirdly, that an individual's decision not to have their comments taped, while respected, would automatically preclude their inclusion in the sample. Despite the researcher's protestations, this committee member insisted that the researcher had an 'ethical' obligation to listen to the patient.

The second, and more insidious, problem arose after gaining approval from Ethics and Research Committees. Persistent difficulty was experienced in actually identifying and then accessing agency gatekeepers to engage their continued support for the study. It is important to identify these individuals to build rapport and provide reassurances that the researcher is acting in the best interests of patient, family and HCP (Minichiello et al. 1990). Furthermore, it has been well documented that health care professionals often project their own fears onto patients when discussing issues related to dying or death (DeSpelder & Strickland 1983; Fulton 1989a; Kübler-Ross 1970) and then decide that their

patients do not wish to discuss such issues with anyone. A situation of this nature arose with a large metropolitan District Nursing Service (DNS).

After the initial written approach to the DNS lengthy personal discussions took place with the Research Advisory Committee who, after detailed questioning concerning the study aims, methodology, and the researcher's credentials, unanimously supported the project. All committee members were very helpful, providing suggestions how best to engage the support of staff providing nursing care to prospective informants. In response to these suggestions several meetings were set up with regional coordinators and supervisors to explain the project and answer any queries regarding the research and allow them to meet the researcher personally. Although the researcher offered to make himself available to discuss any aspect of the research with any individual nurse, supervisors gave assurances that it would not be necessary. During these meetings several supervisors were very 'protective' of 'their' patients and openly hostile toward the research but declined to outline their specific dissatisfaction or concerns. These supervisors accepted the invitation letters, at the same time, declaring that they could not immediately think of any one, within their area, that might be suitable.

Two hundred and fifty invitation letters were given to nine DNS supervisors who undertook to relay the information to other staff and issue the invitations as appropriate. Only one individual contacted the researcher after receiving an invitation letter from a 'relief' nurse. This person initially volunteered to participate in the research, made an appointment for interview, but withdrew her agreement when the researcher arrived to conduct the interview. The reason given for withdrawal of interest in the research was that advice against involvement had been received from the 'regular' nurse. The reason given to the patient by the nurse were that the research was 'of little value to patients'. No informants were actually recruited for the research using this method despite the fact that the nursing service provided domiciliary nursing care to approximately 2,200 individuals with cancer in 1990/91 (Royal District Nursing Service 1991).

A similar situation occurred with the remaining two hospice/palliative care services who, after personal discussions with the researcher, agreed to issue invitation letters to their

patients. In both these cases nurses were responsible for issuing the invitations. No responses were received from patients in either of these programs.

These extreme problems with 'gatekeepers' created major difficulties for the completion of the study in its proposed format. Although access was obtained to a small number of informants, the pool of potential informants was severely restricted. No informants were recruited from the two largest sources of prospective participants, the group of hospice/palliative care organisations and the metropolitan district nursing service.

A further problem concerned access to partners of individuals diagnosed with either HIV/AIDS or cancer. Although individuals with the illness volunteered their participation in the study their partner did not always wish to be included. The option open to the researcher was to either retain or modify the initial selection criteria. Retaining the original selection criteria would necessitate the non-acceptance of single individuals. In view of the mounting difficulties recruiting suitable participants it was decided to review the study's progress and instigate appropriate changes. The difficulties in recruiting sufficient numbers of informants led to the abandonment of the requirement to include couples. Similarly, the difficulties encountered in obtaining partners' agreement to participate in the research led to the abandonment of the requirement to interview partners.

### **Data analysis**

Qualitative data are generally analysed by themes from informants' descriptions (Minichiello et al. 1990). To facilitate manipulation of the data during analysis, the Non-numerical Unstructured Data Indexing, Searching and Theorising (NUDIST) software package was used. The main features of NUDIST are that, it compiles all the documents for analysis (in this study transcribed narratives); it facilitates coding segments of text at defined index categories; it enables easy searching for specific word or phrases in the text of documents; it uses indexing as well as text search as a basis for finding passages of text and the ideas in them; and it allows for the re-organising and extending of the indexing as the study progresses and greater understanding develops (Richards, Richards, Joan & Sharrock 1992). NUDIST supports these processes by creating two systems, the document system and the index system. The document system stores on-line textual documents (interview transcripts) together with data about them that is available for analysis. The

index system stores references to ideas and concepts and facts about the study, and the text units in the on-line text that exhibit those ideas and concepts. This database of concepts consists of 'nodes' which can be linked hierarchically to form any number of 'index trees' of categories, sub-categories, and sub-sub-categories. These nodes are given a numerical 'node address' which is described by a researcher developed 'node title'. These nodes represent the codes developed during the progress of the research.

NUDIST on-line documents must be prepared in specific ways. Initially, each taped interview was personally transcribed by the researcher. This provided a way for the researcher to become completely familiar with the data. To ensure confidentiality, all identifying information was removed during transcription. Deciding how to divide each narrative document into 'text units' was a process of trial and error. Initially, it was thought paragraphs of text would be best. However, preliminary manipulation of the first interview was unwieldy as frequently a number of themes were contained in the one paragraph. Frequently, these themes were presented in parallel. For example, a number of themes are presented in the following extract and, in this format, it is often difficult to tease them out effectively.

- 4.1** Um about 20, 21, quite young. Yeah, and my um experience was only that I'd just finished college and I was about to start, you know, life and I suppose in a new city, I was in ...[named city], so um [EX-WIFE] and I met and I remember having difficulty relating to her sexually at first, but felt quite comfortable because she seemed to deal with that and there was um and that, that fell into place, um but right through the first year of our meeting, because we lived together for a year first, um it was, we never discussed sexuality because we were quite comfortable with each other. I noticed that um I was becoming restless um as far as my feelings towards my sexuality as well, that's just summarising it, it was pretty in-depth, um I remember having an experience, I suppose, in the second or third year into our marriage. (Geoff)

To overcome this problem it was decided to segment each transcript into phrases. As can be seen from the following extract from a NUDIST file, the themes become more easily identifiable. For example, the sexuality theme is easily identified in the emphasised lines (9, 10, 16, 17, 18, 21 and 22).

- 1 Um about 20, 21,  
2 quite young.  
3 Yeah,  
4 and my um experience was only that I'd just finished college

5 and I was about to start, you know, life  
6 and I suppose in a new city,  
7 I was in ...[named city],  
8 so um ...[EX-WIFE] and I met  
9 *and I remember having difficulty relating to her sexually at first,*  
10 *but felt quite comfortable because she seemed to deal with that*  
11 *and there was um*  
12 *and that, that fell into place,*  
13 *um but right through the first year of our meeting,*  
14 *because we lived together for a year first,*  
15 *um it was,*  
16 *we never discussed sexuality*  
17 *because we were quite comfortable with each other.*  
18 *I noticed that um I was becoming restless um as far as my feelings towards my*  
19 *sexuality as well,*  
20 *that's just summarising it,*  
21 *it was pretty in-depth,*  
22 *um I remember having an experience,*  
23 *I suppose, in the second or third year into our marriage,*

## **Coding**

Coding, or indexing, of text units allows them to be retrieved using the NUDIST program. A preliminary system of codes can be developed prior to examination of the data. For example, in the current study codes to distinguishing between the two different diseases, whether they were in a cohabiting relationship and other demographic data can be identified prior to examination of the narratives. Using NUDIST, one code can be applied, as necessary, to the entire narrative. For example, in the current study a code was required to distinguish whether the informant was from the cancer or HIV/AIDS sample. Prior to examination of the narratives it was predicted that a number of probable themes would be present. For example, it was assumed that informants would discuss their diagnosis, treatment, prognosis, the process of dying, the event of death, the state of being dead, culpability, pain, emotional responses, sexuality, disclosure, how others responded, hope and spirituality. Consequently, codes for these topics were also developed prior to preliminary analysis. However, developing a detailed coding system for qualitative data is not a 'one-off' task but rather an on-going process that continues throughout the entire process of data collection and analysis. As each interview is transcribed the narrative is examined to identify themes and codes developed. As new themes are identified in later narratives, the previous narratives are reexamined and re-coded accordingly.

As discussed earlier, preliminary analysis of the pilot interviews revealed that, at different times in their narratives, informants were identified as discussing the issues from different perspectives. For example, these three perspectives are demonstrated in the following composite extract:

**4.2** *I thought I was going to die ....* The doctors talked to me yesterday. They were so positive — about it — tapped me on the back and said. “We’re going to beat it. We’ve beaten it so far and this [chemotherapy] is just what we have — this is just the procedure that we have to go through — and they’re so positive.... *I wanted to know if I was going to die in six — you know, if people get cancer they die six months later.* [Emphasis added] (Sue, 1 271; 874-878; 894-895)

In the first italicised phrase Sue is talking as an individual; she is giving her own opinion about what she thought was going to happen to her. In this instance, Sue is recalling her individual thoughts. There are a number of occasions when other informants discuss their experiences from this perspective. Consequently, it was to identify these concerns that this perspective was coded as ‘individual’. In the second part of the extract Sue is talking about her experiences from a different perspective, one which influences her interaction with the disease and medical staff. Similarly, other informants also used this perspective when discussing their experiences. Accordingly, this perspective was coded as ‘patient’. The last section of the extract (the second italicised section) illustrates the third perspective. Sue is responding with knowledge gained prior to her personal experience of cancer. In essence, she is speaking as a member of the community and relaying an element of the common sense discourse. She is wanting to be informed whether her personal experience will reflect that of the common knowledge. Thus, this phrase was coded ‘community member’.

Detailed analysis is developed by indexing each phrase of text under multiple codes. For example, in the previous extract the phrase “I thought I was going to die” was given the codes ‘individual’ because Sue was talking about her personal thoughts, ‘diagnosis’ because she was talking about these thoughts at diagnosis, and ‘death’ because she was talking about the event rather than the process of dying or the state of being dead. Similarly, the second part of the above extract was coded ‘patient’ because Sue was talking from a patient perspective, ‘doctors’ because she identifies those with whom she was engaged in interaction, ‘hope’ because she uses the language associated with the discourse of hope (i.e., positive), ‘military metaphor’ because she uses language associated with that metaphor (i.e., beat, beaten), and ‘treatment’ because she is talking about chemotherapy.

Using the node building capabilities of NUDIST, a more elaborate indexing 'tree' consisting of branching categories, sub-categories and sub-sub-categories was developed. For example, using the node building expression 'intersect-of' for 'individual' and 'diagnosis' retrieved all the data that was referenced by both these codes. That is, the retrieved data referred to all the occasions informants discussed diagnosis from the individual's perspective. This new node can be given a new address and name and saved for future reference. Furthermore, this process can use multiple codes to retrieve very specific data. For example, by adding 'death' to the above node building expression all text units that refer to individuals who, at diagnosis, discussed personal thoughts about death would be retrieved, including Sue's comment, in the above extract, "I thought I was going to die".

This process of building new nodes was used throughout the process of analysis as the researcher explored the different ways informants' discussed their experiences and the circumstances in which specific issues were discussed. This resulted in a complex indexing system, a copy of which is provided in Appendix G.

Using coding in this way provided the three major foci of data analysis. Firstly, from the informants' perception of the common sense discourse of the respective diseases and illness experience. Secondly, from informants' interpretation of how the medical discourse defines and categorises the diseases and subsequent illness experience, as distinct from the actual professional medical discourse. Thirdly, from informants' developing awareness that their personal experience of the disease and illness differs from their understanding of the common sense and medical discourses. These three ways of perceiving the experience of living with a life-threatening form of cancer constitute the basis for Chapters 5, 6 and 7 respectively. In view of the way knowledge of HIV/AIDS has developed, and informants' responses, a special chapter on interpretation of the medical discourse of HIV/AIDS is not appropriate. Consequently, Chapters 8 and 9 focus on individuals' interpretation of the common sense discourse of HIV/AIDS and how individuals construct their own discourse respectively.



### **Quantitative data**

It was initially intended to use the instruments in Part B of the interview to make comparisons between the two samples and with information in the informants' narratives. Using the Social Readjustment Rating Scale it was hoped to obtain information on significant non-illness related changes that had recently occurred for informants and that may still be affecting their current experiences. For example, the recent death of a family member or friend, divorce or job loss may be influencing individuals' response to their illness experience. However, the small size of the final sample, and the fact that some informants chose to decline completing Part B, led to the abandonment of analysis of the quantitative data.

## **Chapter 5**

### **Influence of the Common Sense Discourse of Cancer**

#### **Introduction**

When individuals receive a diagnosis of life-threatening cancer they are faced with two major dilemmas. Firstly, the diagnosis defines them, physically and socially, as unhealthy. This may occur despite the fact that the symptoms of cancer may not have created noticeably physical problems for the individual (e.g., pain, nausea, restriction of routine activities). Without these obvious physical signs and symptoms the individual may not consider themselves to be unhealthy. As a consequence of diagnosis individuals must engage in the process of reconceptualisation of the self not only as unhealthy, but also as being in a life-threatening situation at a time when they may neither 'feel' unhealthy nor believe that their life is threatened.

Secondly, when individuals' perception of themselves or their subjective illness experience is not congruent with the internalised elements of the common sense discourse they are faced with another dilemma: how to resolve the dissonance between how the common sense discourses describe and categorise the general cancer experience and their subjective encountering of the disease and subsequent illness. Resolving these dilemmas is integral to the process of reconceptualising self-images.

The purpose of this chapter is twofold. Firstly, to identify the elements of the common sense discourses about the life-threatening disease of cancer that, for informants in the current study, create dilemmas for them during their subjective encounter of living with a life-threatening form of cancer. Secondly, to show how these elements influence individuals' initial experiences of living with the disease.

#### **Common sense knowledge about cancer**

Individuals are confronted with the task of reconceptualising the self at three time periods, namely diagnosis, during treatment and when they contemplate their future. At the same

time, within the common sense discourse of cancer a number of different beliefs and practices, that are associated with these three illness-related time periods, create dilemmas for individuals. Some of these beliefs and practices are discussed by the majority of informants, for example, diagnosis of cancer means death; once diagnosed with cancer it is always present in your body; having cancer is a very painful experience and generally results in an agonising death; and diagnosis of cancer significantly changes social interaction with other members of the community. Other beliefs are identified as variations on the theme of these major issues. For example, a number of different ‘causes’ of cancer are identified within the informants’ narratives. Similarly, variations in beliefs and practices related to the treatment theme are revealed.

## **Diagnosis**

The common sense discourse about cancer contains a number of beliefs and practices that focus on, or are associated with, diagnosis. The beliefs most frequently identified by informants in the current research are the link between cancer and inevitable death and that there must be a reason for the development of cancer. The most frequently cited practice is avoidance of the individual by some family members and friends resulting in the loss of routine social interaction.

### **“It’s kind of like a death sentence to people”**

One of the most persistently held beliefs of the common sense discourse about cancer is that diagnosis of cancer is equated with a sentence of death. As will be discussed below, informants openly speak in terms of physical death (see extracts **5.12** to **5.18**, pages 117-118 ). That is, people diagnosed with cancer will ultimately die from the effects of cancer. However, evidence is contained within informants’ narratives indicating that social death frequently occurs prior to physical death.

### **Social death**

Individuals diagnosed with cancer are affected by the practices within the common sense discourse about cancer. Specifically, some family members and friends cease social interaction with the recently diagnosed individual. Buckman (1988, p xiii) suggests that “... most people don’t know how to help, not because of their own failings or inadequacies but because serious illness and the threat of death are very powerful forces”. As a consequence

of these practices individuals interpret the experience as a form of stigmatisation. They perceive that they are being treated as though part of their life does not exist, or in more extreme situations, as if they no longer exist. As a result, individuals perceive themselves not merely socially isolated for a limited period, but actually experiencing a form of social death. That is, relationships are not simply awkward and strained but frequently individuals diagnosed with cancer are perceived as dying and are socially ignored (Kellehear, 1990). Six of the nine cancer informants indicated that part of their social world decreased as a result of receiving a diagnosis of cancer. In particular, the qualities of friendship and family networks were irrevocably changed. These changes in social interaction do not arise from specific comments or statements made by family or friends, verbal disagreements between the participants, or from the inability of the sick person to engage in these routine activities. Rather these changes arise from the common sense discourse practice of avoiding the individual with cancer. For example, two informants speak in general terms about common sense practices associated with the diagnosis of cancer. People respond to them as though cancer is a contagious disease:

- 5.1 There are people who, when you say you've had cancer, they shut up and virtually can't talk to you. (Doris, 1 1672-1674)
- 5.2 You get people coming into your home and they stare at you for hours — and you get people won't drink out of your glass — and you get people — hardly want to know you. (Martha, 1 294-297)

Informants also identify situations where they experience being avoided by family members and close friends.

### *Family*

Three informants speak specifically about the reactions of family members who refuse to talk about the cancer. Furthermore, these family members even avoid inquiring about the individual's health. The consequence of this practice is that an important part of the individual's life experiences is ignored. For example, one informant, who considers that she has a close-knit family, was visibly distressed as she recounts her brother's reaction:

- 5.3 When I got the cancer he never spoke to me about it. He's never asked how I am. He's never questioned. (Doris, 1 1765-1767)

Similarly, a second informant, who was in hospital recovering from surgery at the time of interview, describes her sole sibling's reaction:

- 5.4** My sister hasn't even come to see me. She can't ... when she found I had cancer she couldn't talk to me. (Sue, l 359-367)

This situation is particularly difficult for this informant as she had experienced her father's death from cancer three years prior to her own diagnosis and her older brother's suicide one year prior to the current research interview. Consequently, as the only remaining sibling, the sister's actions are interpreted by the informant as particularly hurtful.

The third informant specifically links the general community practices of the common sense discourse about cancer and her family's reactions when she states:

- 5.5** ... the word cancer — you know it's horrific because your family disown you — my family disowned me [long pause] [very upset] my brother and all. (Martha, l 288-290)

### *Friends*

Five informants speak specifically about the common practice of some members of the community who failed to contact them after hearing of the cancer diagnosis. In most instances these former friends did not provide any reason for discontinuing contact with the informant. Their reaction was not to make contact with the informant, or if contacted, to remain distant. For example, one informant not only speaks about former friends' failure to contact her after diagnosis but also what occurred when she made the effort to make contact:

- 5.6** I've had friends that I thought were my best friends — and I haven't seen them — since I found out [diagnosis]. And when you ring 'em up *it's like talking to a complete stranger. They just can't deal with it.* [Emphasis added] (Betty, l 1732-1738)

Although Betty does not specify what actually occurred during her interaction with these friends, the significant point is that Betty symbolically designated her friends' verbal and non-verbal behaviour as indicating that they were distancing themselves from her. Betty also provides her interpretation for these former friends becoming 'strangers': they are unable to cope with Betty's diagnosis of cancer and its implications.

Similarly, another informant speaks of her surprise at the reaction of some of her friends:

- 5.7 There are quite a few people that surprised me — uhm — that we never saw them again, or we rarely see them, or *you get this feeling that they'd rather not see you*. [Emphasis added] (Jan, 1 1925-1928)

This extract further demonstrates the fact that individuals make interpretations of interaction with former friends. In this instance, Jan interprets her former friends' behaviour as indicating that they feel ill at ease interacting with her and would prefer to avoid future social contact.

Other informants identify the common sense practice of avoidance by former friends and, at the same time, provide an interpretation of the reason for their behaviour as well as identifying their emotional response. One informant angrily states:

- 5.8 I had hundreds and hundreds of friends — some of them are frightened to come and see you because they think they're going to catch it [cancer], or they're not going to see you again, they're scared for themselves ... it's a disease ... it's — you're dying — some of them they haven't got the time of day [for you]. (Martha, 1 1156-1164)

Martha also observes that her friends' behaviour after her diagnosis is different to their pre-diagnosis behaviour. Martha's interpretation is that her former friends react this way because they think cancer is contagious and they will 'catch' cancer (see also extract 5.2 page 112). Martha makes the further interpretation that these people fear for their own health and life.

Another informant expresses sadness at her friends' reaction to her return home from hospital after initial cancer-related surgery. At the same time she suggests a reason for their action and a solution to maintain social interaction:

- 5.9 A couple of friends couldn't bear to come and see me — when I came home [from hospital] and I was a little bit sad about that — *but then again, when I looked in the mirror I looked like a skeleton, no hair, and I looked positively shocking*. And I thought 'Well, I don't really want them to see me anyway', so I said, "Look, don't visit me. Ring me up." So we'd sit on the 'phone and have a yap for about an hour. I'd feel better and they'd feel as though they'd done me a visit. [Emphasis added] (Dulcie, 1 492-495)

The process of role taking is clearly demonstrated in this extract. Social interaction is initially disrupted by Dulcie's friends' inability to see the physical ravages of the disease

and treatment. Dulcie's initial response to this situation is to feel "a little bit sad". However, in contemplating her mirror reflected self and her then situation she not only acknowledges to herself that she looked "positively shocking" but also recognises that her friends would probably experience a similar response. Dulcie resolves the non-visiting situation by suggesting that her friends make regular telephone contact with her rather than personal visits. This new situation is acceptable to both Dulcie and her friends. More importantly it results in the continuation of mutually satisfying social interaction.

One informant not only cites the avoidance practice carried out by friends, but also provides another opinion as to the reasons for these practices: people's dislike of facing their own mortality.

**5.10** I'm interested in observing people too, observing me sort of stuff — and — I can see avoidance — all sorts of stuff like that. I think — there are very, very few of my friends — the friends, or acquaintances, which ever way you want to put it, that uhm — we had before I got cancer that I still regularly see ... I'm very well aware why people avoid you while you're ill — .... People don't — *because people don't like to face their own mortality*. [Emphasis added] (Jan, l 1532-1547)

Finally, one of the informants acknowledges that she too had engaged in the common sense practice of not visiting friends who had been diagnosed with cancer and was now on the receiving end of such practices:

**5.11** Another friend ... got cancer and she went [died] within six months and I couldn't accept it. I couldn't go and see her, and then I felt so guilty when she died and I have to live with that guilt ... I have a girlfriend who can't accept the fact that I've got cancer too. I've known this girl since we went to school together, and we'd always been fairly close. Now she can't even talk to me on the 'phone. (Doris, l 1418-1471)

The previous six extracts identify examples of how social relations are disordered, sometimes to the point of complete breakdown. Crawford (1994) uses a structuralist perspective to suggest that this disruption to social relations is due to the inability of the seriously ill person to perform social roles and obligations. However, the above extracts cast doubt on this explanation. It is not the individual with cancer, but rather the healthy family member or friend who, through active avoidance of the sick individual, who does not engage in routine social interaction.

Symbolic interactionism provides a different explanation. As discussed in Chapter Two human conduct occurs in specific, concrete and usually well-known situations that present individuals with acts and social objects in familiar configurations. Where a situation is familiar and its configuration of meaning is known, individuals organise their own conduct and their expectations of others in relation to its definition. Definition of the situation provides individuals with information about what is occurring and who is making what happen. Consequently, they are able to see who they are and what they are supposed to be doing (Hewitt 1997). Although the common sense discourse of cancer provides healthy individuals with ways of talking about cancer among themselves, there are still a number of unknown aspects relating to cancer (e.g., why cancer develops in some situations and not in others (Lowenthal 1996)). The conflict between a number of commonly accepted beliefs (e.g., cancer means death, the hope for a medical cure, the causes of cancer are unknown, and cancer might be contagious) also results in confusion for healthy members of the community during interaction with the individual diagnosed with cancer. Furthermore, the serious nature of cancer confronts the healthy individual with their own mortality (Siegel & Weinstein 1983; Taussig 1980). The existence of a number of unknown social objects associated with diagnosis and treatment of cancer results in an ill-defined situation. Hence, information about what is taking place and who is making what happen is either ill-defined or non-existent. Since the causes of cancer are not always known medically, reasons for developing the disease are socially constructed. Many healthy members of the community do not know how to interact with individuals who are living with a life-threatening disease (Buckman 1988). As a result they avoid social interaction. This reaction of family and friends serves to reinforce the sense of separation and 'otherness' for the individual. In turn, this heightens individuals' perception of guilt for their imagined wrongdoing. This sense of separation from routine social interaction is augmented by practices within the medical discourse (see Chapter Six).

There are a number of implicit messages conveyed by this practice of avoidance. As a number of the informants identified in the above extracts they 'receive' the message that these family members and friends are not able to cope sufficiently with the individual's diagnosis of cancer to enable them to maintain basic social interaction. The critical message



this communicates to sick individuals is that they must cope with cancer without the routine social support that was available during much less critical events and that they had come to expect. Quite clearly another message is to be careful with whom these highly emotive issues are discussed. Since some people are unable to incorporate into the routine of their daily life a close associate's diagnosis of cancer, disclosure of such information by the patient is highly likely to lead to some form of rejection and exclusion from routine social interactions.

### **Physical death**

The belief that diagnosis of cancer means certain death has been a long held element of the common sense discourse about cancer (Lowenthal 1996). For example, one informant has been living with various forms of cancer since receiving the original diagnosis of cancer of the cervix in 1965. In discussing her reaction to this initial diagnosis of cancer the informant states:

**5.12** They said I had these cells — abnormal cells, and I said “What do you mean by abnormal cells?” and they said “Cancer of the cervix” and I said “Right, — ahh — cancer — they cut you open and you die” ... you didn't have — uhm — radiotherapy, chemotherapy, you didn't have any of that in those days. It was they cut you open and a lot of people died. (Josie, l 144-160)

The strength of this aspect of the common sense discourse about cancer is evident in the fact that it still exists within the Australian community, despite the extensive community education campaigns developed and implemented by organisations such as the various State Cancer Councils (e.g., Anti-Cancer Council of Victoria 1995, 1997b, 1997a).

In providing information on her experiences with other individuals with cancer one informant makes the comment:

**5.13** Some people, as soon as they hear the word cancer they — think they're dead already — you know, it's kind of like a death sentence to people. (Dulcie, l 1166-1167)

Throughout her narrative Dulcie also acknowledges that she too thought that she would die as a result of developing cancer:

**5.14** I thought I was going to die anyway, — and I thought, ‘Oh well, so what! What's another thing’ [chemotherapy]. (Dulcie, l 122-123)

**5.15** Oh yes — I thought I would die — that’s what I said, you know, I’m laid back there [on the hospital bed], my arms folded like this [across chest as if laid out] “Do your worst. I’m ready [to die].” (Dulcie, l 1425-1428)

This extract is also indicative of the implicit common sense discourse belief in the limited benefit of treatment. Dulcie is symbolically saying that she believes there is nothing that can be done to cure the cancer. This was influenced by her personal experiences when her father had cancer, albeit some forty years earlier. In telling her illness story, Dulcie makes the following comment:

**5.16** And not knowing anything about chemotherapy at this time, you think to yourself, “Oh I don’t know”. My Dad had chemotherapy and they told us “Waste of time”. Why did they put him through it? (Dulcie, l 1723-1725)  
Although ostensibly providing information about her father’s experience there is a sense that Dulcie is also raising the issue in her own situation. It appears that Dulcie still suspects that chemotherapy is a “waste of time”.

Another informant voices a similar opinion about cancer and physical death:

**5.17** I thought I was going to die ... I wanted to know if I was going to die in six — you know, *if people get cancer they die six months later*. [Emphasis added] (Sue, l 271; 894-895)

A third informant, who worked as a nurse, until a major motor vehicle accident six years prior to her diagnosis of ovarian cancer, makes the comment about her response to the initial diagnosis:

**5.18** And of course cancer, — I worked with people with cancer, years ago, and the first thing you think of is death ... Because the word cancer — cancer is cancer and you’ve got the disease and that’s that — and you’re going to die anyway from it. (Martha, l 75-77; 2183-2189)

In this extract Martha demonstrates the important dilemma concerning the conflict between self-images: former nurse versus current patient diagnosed with cancer. Martha uses prior medical experiences gained while working as a nurse to reconceptualise her current self-image as a cancer ‘victim’.

The anti-cancer campaigns may have decreased the explicit statements, such as those expressed in the above examples, but the pervasive influence of the common sense

discourse is such that the belief linking the diagnosis of cancer and death is still current. However, expression of the belief is now more covert and implicit, for example:

**5.19** Once you've got cancer you're never really free of it. People say — "Yes we've got it — it's gone", but it's never gone. It's always there. (Josie, l 1636)

What Josie implies in this comment is that cancer is never completely eradicated from the body. It may be dormant for some time but sooner or later it will begin to regrow and eventually be the cause of the individual's death.

In some instances informants reverse the anti-cancer campaign's slogan "Cancer is a word not a sentence" thus providing some form of 'official' validation to the belief in the link between cancer and death:

**5.20** You see it's a *life sentence* — it's not something that — you've had an operation, like, you know, your appendix got sick and you took it out and you were better after that — 'cause cancer's not like that. It's an ongoing life thing whereas — uhm — I've had it once — it could come up anytime and it could flare up anywhere else. [Emphasis added] (Betty, l 1889-1896)

Betty's comment supports the implicit message in Josie's previous extract. That 'once a cancer patient, always a cancer patient'. Also implicit in Betty's comment is support for the belief, expressed by Dulcie (see extract **5.16** page 118), that treatment for cancer is never completely successful, as it can not totally eradicate cancer cells from the body.

Although the recent development of more sophisticated diagnostic techniques and procedures have resulted in the earlier detection of cancer, which in turn provides earlier opportunities for intervention therapies that increase chances of survival (Lowenthal 1996), the link between cancer and death still exists. Although various forms of therapy are currently available these are often considered as only extending life for a limited time. For example, a woman in her mid fifties who had undergone extensive surgery and then both chemotherapy and radiotherapy discusses the possible causes of her death. Notwithstanding the fact that she indicates it is possible that she might die suddenly as the result of some other, unpredictable cause for example, being "run over by a bus", she states:

**5.21** But I'd say nine out of ten chances it'll be — cancer that will take me off anyway. (Doris, l 1894)

This belief is also expressed symbolically by a number of informants. For example, one informant uses a scene from a local television soap opera (a major transmission mode of common sense discourses) to highlight the implicit link between a diagnosis of cancer and inevitable death:

**5.22** Something would happen on TV and you'd be here crying your eyeballs out and the kids are going "It's OK Mum. It's only a movie." But it's like, it's not a movie. It's like — you know — a bit more than a movie —. I don't know what I was watching one night and it was something about this kid who was dying of leukemia, or something, and I thought "*God! I can associate with that!*" [laughs] —. It was on Home and Away and — she just sort of said, you know, like "But it never finishes!" — because even in the character she was playing — someone had asked her "But when you go into remission it's over" and she says "No, it's not. It's never over. I might be in remission but for how long? — months? — years?" She says "Nuh — it's always there." [Emphasis added] (Betty, l 2018-2037)

Embedded in this extract is the informant's personal belief that diagnosis of cancer is equated with a death sentence. Betty is using the metaphor of a popular Australian soap opera to indicate support for her own belief about cancer and inevitable death.

Another informant compares cancer to other potentially life-threatening experiences. Although recognising the hardships associated with recovery from these incidents she uses symbolism to indicate her belief in the fatal nature of cancer and its effect on individuals.

**5.23** Having a stroke and a car accident it was hard — but having cancer it was the end — you know, *cancer is no return* — because every time you looked at yourself you'd see a skeleton. You don't really see yourself .... Every time you looked in the mirror the only thing you saw yourself as a skeleton — and every day that goes by, every hour, every minute, the only thing you think about is coffins — and you get — already in the coffin ... I saw death every day — and coffins every day — and — no matter what I tried to do ... think about death every day. [Emphasis added] (Martha, l 122-124; 539)

This extract also exemplifies one aspect of the struggles some individuals have in reconceptualising their self-images as being in a life-threatening situation. Martha has considerable difficulty developing a self-image relative to her current situation. She sees the mirrored reflection of her future self in symbolic terms: the skeleton represents her own death. This is supported by the symbolism of her thoughts: inevitable death, again being represented by coffins. At this point in her narrative she perceives herself as having a

terminal disease. Thinking of herself as constantly in a coffin also symbolises both her feelings of being trapped by the disease and ultimate separation from the world of healthy family members and friends. However, during the interview Martha oscillates rapidly between these images of death and being influenced by the discourse of hope by indicating that she is not going to let the cancer 'beat' her.

Other informants also use symbolism to imply the link between cancer and death. For example, on receiving confirmation of the original diagnosis, Fred simply indicates his reaction was:

**5.24** I thought the end of the world was comin' — to be quite honest. (Fred, l 219)

In discussing the treatment she has received and her future, Josie comments:

**5.25** Unfortunately for me there doesn't seem to be a light at the end of the tunnel because it [cancer] always comes back. It doesn't matter how far — how much they cut, how much they burn, what they do, it always reoccurs. I didn't see a great future. I just saw myself — getting this [cancer] all the time — being in and out of hospital all the time, and probably, one day, — not coming out of hospital. (Josie, l 647-656)

In this extract Josie demonstrates that, although she has had cancer for over twenty eight years and kept 'fighting' for survival, she is beginning to acknowledge a new self-image as a person who will not survive and will eventually die as a result of cancer. Like Martha and Sue (see Chapter Seven), Josie oscillates between the 'positive' self-image of beating the cancer and this newer self-image of someone who will be 'overcome' by cancer.

This firmly held belief that diagnosis of cancer is equated with a sentence of death, in conjunction with the practice of avoiding the individual with cancer, implicitly conveys community expectations. Not only is the individual with cancer required to face their impending death with restricted social support but also they must face treatment and death bravely. This issue of bravery is discussed in more detail later in this chapter.

### **Reason for getting cancer**

As one of the modern disorders that carry the most powerful symbolic loading, cancer forces the community to confront its lack of control over death (Lupton 1994a). More fundamentally, it symbolises the community's need to make moral sense of why the disease

develops. It is commonly believed that this moral explanation is lacking in the explanations of scientific medicine; ‘Why this particular disease?’, ‘Why this particular person rather than any other person?’ and ‘Why now?’. This attempt to make moral sense of the situation generally occurs at, or soon after, diagnosis as individuals interact with the knowledge of their diagnosis of cancer. For example, Sue, who was diagnosed with cancer of the cervix three weeks prior to interview, struggles with her attempts to understand why she has developed cancer rather than other more ‘deserving’ people and why she had cancer now, particularly after all the difficulties that she has been through during the last three years:

**5.26** Why me? Why should I be the one to get this and not him? [husband] — ‘Cause, sort of, my family’s had it hard in the last — nine years. My dad had a tumour on the brain for nine years. So he died three years ago — and my brother committed suicide last year and now we’ve got this ... why could this happen to us, to my family, and me? ... you look at all these ones — rough people, you know, on the streets and things like that. Why don’t they get anything? It’s not fair. (Sue, 1103-129)

Sue partially demonstrates in this extract the “vortex of the most fundamental questions concerning life and death” raised by Taussig (1980). This issue is expanded in more detail in Chapter Six.

Individuals living with life-threatening forms of cancer reflect the community need to make sense of developing the disease by asking ‘Why me?’. Traditionally, within the medical discourses about dying and grief, the phrase ‘Why me?’ has been perceived as an indicator that the individual is in the stage of anger (Kübler-Ross 1970). However, although the expression of anger may be associated with this specific comment, it has been proposed that this particular phrase is more appropriately viewed as a reflection of the individual’s need to make sense of the unpredictability and uncontrollability of cancer as well as their life-threatening illness (Fulton et al. 1996). As the following discussion demonstrates, this argument is supported by data in the current study.

Individuals diagnosed with cancer are surrounded by notions of moral culpability (Lupton 1994a). Sontag (1991) suggests that, in modern Western societies, cancer is often viewed as a disease brought upon oneself through irresponsible behaviour, either by indulging in injudicious diets, exposure to carcinogenic substances, or by suppressing negative or angry

thoughts. Developing cancer is represented as punishment for living an unhealthy life, taking health risks, dietary and lifestyle excesses, weakness of will, self-indulgence and addiction.

Informants in the current study provide a variety of explanations for the development of cancer. These include exposure to carcinogenic substances, as a form of punishment, exposure to excessive stress and as an opportunity for personal growth.

### **“Do you think it was caused through me smoking over the years?”**

To date there are a number of known carcinogenic substances that have been identified by medical science (Bates & Linder-Pelz 1990). Substantial publicity linking specific carcinogenic substances to particular forms of primary cancer (e.g., asbestos dust and mesothelioma, tobacco and lung cancer) has also occurred. The high profile public debate about smoking and lung cancer, that has led to prominent display of medical warnings on cigarette packets, also has led to the link between smoking and lung cancer being entrenched in the common sense discourse about cancer. Consequently, individuals now diagnosed with lung cancer invariably attribute the development of the disease to prolonged periods of smoking. For example, Fred was initially diagnosed as having oesophageal cancer, and underwent surgery. During a routine post-operative check-up some eighteen months later secondary cancer was detected in his lung. Fred's initial reaction to the information was confusion. He was unable to understand why the lung cancer appeared. After treatment for the secondary cancer in his lungs he was still attempting to understand why he developed lung cancer. Influenced by beliefs within the common sense discourse, and not fully comprehending the medical discourse, he thought his metastasised cancer was caused by his years of smoking and sought verification:

**5.27** And I asked the doctor ... “No w with this lung cancer ... do you think that was caused through me smoking over the years?” — and he didn't sort of give me a direct answer. He said “Oh it could have been or it may not have been”, you know, just like that. (Fred, 142<sup>9</sup>-437)

### **Punishment**

Another very powerful belief, within the common sense discourse about the cause of cancer, is that the cancer occurs in response to some wrongdoing. This may be in response to an act of commission or omission on the part of the individual or their family. The

foundation for this belief may be in either religious or moral precepts and has a number of variations. Several informants grappled with the issue of punishment in their attempts to make meaning of why they developed cancer. These included the possibility of divine intervention, not working hard enough, and not taking enough care of one's health.

**“God wouldn't be cruel enough to do this to me”**

An informant who was diagnosed with a life-threatening form of cancer three weeks prior to interview demonstrates the tension individuals experience as they search for reasons why they developed cancer. In interaction with the diagnosis of her cancer, this particular informant raises a number of possible causes before suspecting that her cancer might have been caused by divine intervention. Sue, a twenty-four year old mother of two young children, was interviewed in hospital as she recovered from the effects of surgical treatment for cancer of the cervix. With a sense of desperation she struggles with a number of commonly expressed reasons for the development of cancer. Initially she rails against the injustice of her cancer, even suggesting that it wasn't fair that she should get cancer and not her husband (see extract 5.26 page 122). She thinks that she, or her family, is being punished for something but could not identify what she had done wrong to 'deserve' to get cancer:

**5.28** Why me? Why — I didn't do anything wrong. (Sue, l 123)

In her attempt to find a reason for her current experience, Sue suggests that it was unfair that she has cancer when there were people who were more 'deserving' of developing cancer:

**5.29** And you look at all these ones — rough people, you know, on the street and things like that. Why don't they get anything? It's not fair. (Sue, l 124-129)

Implicit in this statement is the common sense discourse belief that development of cancer is a suitable 'punishment' for immoral behaviour or social problems (e.g., homelessness). It also demonstrates the dichotomy between the healthy, responsible self and the irresponsible, unhealthy other. At this point in her illness experience (three weeks after diagnosis) Sue clings to her perception of self as responsible and healthy and, like healthy members of the community, attempts to project her disease onto unworthy others.



Finally, in her turmoil, Sue demonstrates another aspect of the common sense discourse in that she questions her religious faith. Although some part of her 'knows' this is not the case, another part of her suggests that God might be responsible for sending the cancer:

**5.30** I just think God wouldn't be cruel enough to do this to me. [Begins to cry] *But I don't know sometimes.* [Emphasis added] (Sue, 1 511-512)

There is no doubt that this particular informant was still in a state of shock at the time of interview. Her original visit to her doctor had taken place only three weeks prior to the interview. In the intervening time she had been referred to a specialist gynaecologist. She was immediately referred to a surgeon who recommended an urgent surgery (radical hysterectomy and removal of her lymph glands). After surgery she was informed that her course of chemotherapy would be at the same location her father had received 'unsuccessful' treatment for nine years prior to his cancer-related death. Sue's responses accurately reflect individuals' attempts to make meaning of their cancer diagnosis. In a relatively short time period Sue has been confronted with a number of new situations that have multiple new objects with which she must interact, interpret, and to which she must ascribe meaning. The above extracts reflect her attempts to make meaning of one aspect of her diagnosis, namely, its cause. She interacts with a number of different 'causes' that are suggested by the common sense discourse of cancer, mentally applies each cause to her own situation, assesses its applicability before 'rejecting' it and moving on to another cause. Finally, in her attempt to make moral sense of her situation she contemplates whether she is being subjected to divine retribution. To aggravate her situation Sue is also attempting to integrate her understanding of her current situation in the broader context of her family's recent experiences (see extract **5.26** page 122). The above extracts also demonstrate Sue's struggle with reconceptualisation of her self-images.

The above 'cause' also highlights the theme of punishment that is an integral part of the common sense discourse about cancer. However, for the individual, none of the taken-for-granted reasons for developing cancer are useful in assisting her to make meaning of her illness experience. Fluctuating between a number of possibilities she is presented with multiple dilemmas which create greater confusion and emotional pain for her. Understandably, by the time of interview, Sue has not been able to resolve the question of what caused her cancer. Sue continues to return to this issue throughout the interview,

fluctuating between her self-images of being healthy rather than having a life-threatening disease, of having cancer but beating it, and of dying as a result of cancer.

**“Maybe if I’d worked harder, would it have been different?”**

A variation on the punishment theme, and an example of the strength and influence of the belief that there is a cause for the development of cancer, is demonstrated by one of the informants who was initially diagnosed eighteen months prior to interview:

**5.31** I was so angry at me [tears being shed quietly] — ... because — I didn’t expect, all my life being a battler, — and that had to happen ... ’cause I worked hard all my life — and maybe if I worked harder — would it have been different? I was angry at me -- ’cause of everything that happened in my life — out of all the children [Martha’s siblings] it’s always me. (Martha, 182-96)

This extract demonstrates a number of complex, yet interrelated issues. Firstly it demonstrates the previously discussed issue of the individual’s search for meaning. Martha’s attempts to find meaning demonstrate a second issue, the common sense discourse belief in the culpability of the individual: it is her fault for developing cancer. This issue is bound up with the third issue: the influence of the common sense discourse belief that cancer is punishment for some wrongful action. Consequently, Martha wonders whether the cancer occurred because she did not work hard enough. Finally, it demonstrates the emotional response to this confusing situation. This emotional response is also interwoven with the common sense discourse belief in the individual’s culpability. Martha states that she is angry with herself: she thinks she ‘caused’ the cancer through her own actions by not working hard enough. This response is sanctioned by the common sense discourse: since the individual is responsible for development of the cancer then it is only appropriate that she must express anger at herself. However, what is really the cause of her anger is her perception of the injustice of the situation. To add to her anger, the cancer experience seems to be a reflection of the rest of her life where she sees herself to be the ‘victim’ in her family.

**“Why didn’t you look after yourself”**

Another variation of the punishment theme is the practice of blaming the individual for not taking ‘proper’ care of themselves and therefore developing cancer. This response is also associated with the common sense discourse beliefs about personal culpability, avoiding contact with known, or suspected, carcinogenic substances (e.g., some food additives) and

that eating the proper diet and maintaining a 'healthy' lifestyle will ward off cancer. One informant recounted an interaction she had with her mother some months after her diagnosis and during her course of treatment:

**5.32** She said to me, you know, like: "Parents are supposed to die before the kids. How dare you get sick!" — you know, like it was all my fault. And she wasn't kidding either. It was all my fault! And — you know, "Why didn't you look after yourself?" I said "Mum, how was I supposed to know I was going to get cancer?" I said "Who knows? It happens to anybody." "Yeah, but why did it have to happen to you?" You know, "You the fitness freak — and — the health freak". (Betty, l 1803-1807)

The questions raised by Betty's mother are rhetorical. They are a verbalisation of her own attempts to find sense and meaning in the unpredictability and uncontrollability of a disease that had already claimed the life of her husband and is now in the process of claiming her daughter's life (Betty died six months after the interview). In addition, these questions were intricately connected with the discourses about dying and death. The common sense discourses about dying and death include entrenched beliefs that there is a 'natural' order associated with death which says that parents will die before their children. Hence Betty's mother is struggling to resolve the tension that existed within her concerning the multiple common sense discourses about cancer, dying and death and the reality of her current experience associated with her husband's, and now her daughter's illness experience. It would seem that in blaming Betty, her mother is warding off her own fears of developing cancer. Her actions are an attempt to distance herself from her 'unhealthy' daughter, and all that is implied in that label, and construct her own self-image as a responsible person who looks after herself and, therefore, would not develop cancer.

More importantly, the tension created by these accusations of carelessness also has substantially negative effects on Betty who is not able to obtain emotional or practical support from her mother. On returning from one of her many hospital visits Betty comments:

**5.33** She took one look at me and burst into tears and said "That's it! I can't cope!" and went to her room. It was as if she'd — you know, given up on me and I thought, 'Am I that bad?' I didn't think I looked that bad — and the whole time she was there she spent more time outside than she did inside with me — she couldn't cope with it — so I asked her did she want to go home. (Betty, l 1755-1765)

This is another example of the 'healthy, responsible' person not knowing how to interact appropriately with an individual diagnosed with cancer. Betty's mother is not engaging in the process of role taking. Therefore, she can not see the world from Betty's perspective. She does not take that perspective into consideration during interaction with Betty. As a result, she is unable to identify what emotional or practical support Betty requires. This social interaction between mother and daughter, or ill person and carer, is unsuccessful. The situation is resolved by the ill person (Betty) taking on the role of her 'caring' for her mother by relieving the stress and tension. Firstly, without needing to raise the issue explicitly, Betty recognises her mother's inability to cope. Betty does this by taking on the roles of her mother (as carer, widow, mother of a terminally ill child) and perceiving that her mother is experiencing difficulties because of past experiences (her husband's death from cancer). Secondly, Betty, still in the role of carer, offers her mother a way to resolve her 'dis-ease' by asking her did she want to return to her own home in the country.

In the absence of data collected from Betty's mother it is not possible to accurately identify the reasons why Betty's mother did not engage in role taking. However, it is possible to suggest possible explanations for her behaviour. Firstly, she may be overwhelmed by the fact that her husband had already died as a result of cancer. This previous experience may reinforce the belief, within the common sense discourse, that cancer is a death sentence. This may override her commitment to the discourse of hope. Secondly, she may be afraid of taking on the cancer patient role because it may be 'tempting fate' too much and she, too, may develop cancer. Thirdly, she may experience difficulty taking on the cancer patient role because the common sense discourse does not include ways of talking about the disease or illness experience from the patient's perspective. Instead, beliefs within the common sense discourse of cancer suggest that the ill person is 'responsible' for their health status and the way to interact with patients is to encourage them to take on this responsibility, exert their will power and change the course of their disease.

### **“Stress brings out the cancer”**

A further commonly held community understanding for developing cancer is that it results from exposure to excessive 'stress'. Informants in the current study canvass several

variations on the stress theme. One informant, and her mother, believes the cancer may have resulted from the stress associated with her brother's suicide:

**5.34** ... 'cause suicide especially, that's the worst thing you can ever go through 'cause you don't know why he did it — never know why — ... I didn't expect it — that's what Mum thinks brought this on [cancer] — 'cause they say shock and that brings out — and stress brings out the cancer and she thinks his death did this to me ... because I never accepted it from the start [brother's suicide] and I didn't — and I still don't. (Sue, I 1126–1140)

Again Sue demonstrates the difficulty of the struggle in which she is actively engaged: attempting to reconceptualise her self-image. She is attempting to accept that she has been diagnosed with a life-threatening form of cancer and with the consequence that she is no longer a healthy member of society. Firstly she focuses on her brother's suicide as the stressful event responsible for her cancer. Despite detailing, during the interview, how difficult it was to regularly visit her father in hospital and watch him suffer and deteriorate over a nine year period Sue does not include this stress as a cause of her cancer. This example also demonstrates the inconsistency and lack of systematic codification of knowledge that is a characteristic associated with any common sense discourse. Although exposure to excessive stress is believed to 'cause' the development of cancer there is no methodical identification of the various forms of 'cancer causing' stress and the difference between this 'excessive' stress and the 'routine' stress of daily living.

Another informant who, in providing an account of her life prior to cancer, speaks of the dramatic changes in her life, thus raising a variation of the stress theme. She indicates that she and her husband had been very comfortable financially as they owned two houses in affluent suburbs – one within the metropolitan boundaries of a large Australian city and one in a fashionable holiday resort – and sent their children to prestigious private schools. However, their business was declared bankrupt and they were forced to sell everything and rent a dilapidated house, due for demolition a month after the research interview. Doris makes the casual comment that the bankruptcy occurred:

**5.35** ... before the cancer. Two and a half years ago — a bit longer — before the cancer started —. Maybe it was that that started it. Who knows? — it [bankruptcy] was a heck or a shock. (Doris, I 2009-2017)

The manner in which Doris comments on this issue raises the important point of whether she really believes this to be the cause of her cancer. It appears as though Doris is experiencing, like other informants, some tension between the common sense discourse belief about causes of cancer, the medical discourse and her own experience. Despite this commonly accepted link between stress and cancer it appears as though Doris is actually questioning the accuracy of this belief. At this point in her illness experience (two years after surgery) she is only 'toying' with the notion of personal culpability. This issue was raised by another informant who makes the comment:

**5.36** ... [I'm] not saying I'm responsible for it [cancer] in the sense that I gave it to myself even 'though there may be some issues there like stress issues and so on that I've definitely done to myself. (Jan, I 786-788)

Another informant provides a further variation on the stress factor causing cancer. In detailing some background information on the various forms of chemotherapy Fred speaks of his friend's experience in developing cancer. In this example the stress causing the development of new cancer is physical rather than emotional:

**5.37** She started off with breast cancer, like an average woman goes through, then she had a bit of other cancer, sort of thing. Well now — she was a barmaid down the hotel and she slipped one day on the lino, the wet lino, she slipped, and apparently came down on her hip. Well now anything like that with her — ahhh — straight away will set off cancer — which it did. (Fred, I 234-241)

The other point raised in this extract is the difference between the common sense and medical discourses about cancer. In this instance, and with stories about his own cancer, Fred does not appear to be aware of one of the major concepts within the medical discourse, that is, that cancer metastasises (i.e., cancer cells spreading from one part of the body to another through the bloodstream or lymphatic vessels). As in his own situation of secondary lung cancer, Fred understands that his friend's metastasised cancer is a new, independent cancer that was caused by her accidental fall.

### **“Illness is a teacher”**

An alternative common sense discourse belief, concerning the development of cancer, is that a life-threatening illness experience is 'sent' to provide the individual with the opportunity for personal development. This appears to be gaining in popularity over recent years and coincides with the discourses about dying and death and the hospice/palliative

care movement that focus on the quality of life and terminal illness providing people with the opportunity for the resolution of personal issues or problems. This is commonly referred to as completing “unfinished business” (DeSpelder & Strickland 1983; Peterson et al. 1992). It also coincides with the proliferation of the general personal growth movement that focuses on quality of life and taking responsibility for dealing with personal issues (e.g., King 1988)). This idea can even be found within the medical discourse. In a book aimed at ‘informing’ patients of a variety of aspects of cancer in the 1990s Lowenthal (1996, p. xi), the director of medical oncology at a metropolitan hospital claims that the diagnosis of cancer “can bring new insights into the joys of living to all involved .... [and] much to do with cancer is happy and hopeful, and *all of it is an adventure* [Emphasis added].

One informant, who had been involved in a specific self-awareness program, perceives her illness experience as a ‘teacher’. Although she had encountered considerable difficulties during her illness she speaks in glowing terms of her overall experience:

**5.38** I have more a feeling of peace now than I’ve had for a hell of a long time. It’s like I’ve been through this process of struggle and — working through all these underlying emotions — and it’s just come out to where I am now ... I was on a journey before — but it’s like, intensified with the illness, like — you know, — ... it’s intensified it’s — uhm — the journey’s intensified with the illness. *Like illness is a teacher ... I wouldn’t have missed this last eighteen months for quids.* [Emphasis added] (Jan, 11777-1793; 1847)

This particular informant and her husband, who was diagnosed as being HIV-positive, had both attended a self-awareness course called *The Forum* and were both adherents to its ideas and practices. Jan recounts that throughout her illness experience, as with other personal experiences in her life (e.g., husband’s disclosure of his homosexuality, husband’s seroconversion), she has looked for the ‘lessons’ each episode has ‘provided’ for her.

The common sense discourse reasons why people develop cancer serve to make the individual with cancer responsible for their disease. At the same time they ‘safeguard’ the healthy members of society by reinforcing the belief that only irresponsible members of the community develop cancer because they do not take proper care of themselves, they do not

have sufficient willpower to maintain a healthy lifestyle, or they have done something wrong and deserve to be punished.

## **Treatment**

The common sense discourse about cancer contains a number of treatment-related beliefs and practices. These are often expressed in a constellation of metaphorical systems (Lupton, 1994) that frequently make moral judgements about the individual and are often perceived as a way of taming or defeating death (Sontag, 1991). One metaphor dominates the response to cancer: the military metaphor.

### **The military metaphor**

The common sense discourse about cancer includes the belief that ‘winning’ the ‘war’ against cancer is intimately linked with the patient having a positive attitude to getting better. In addition, this metaphor implies the need for willpower to defeat the enemy and ‘recapture’ a healthy physical and social status. Individuals with cancer, who appear ‘brave’, never allowing themselves to ‘surrender’ to the disease, are extolled. When used in relation to a life-threatening illness the military metaphor serves to make individuals responsible for their illness and its outcome. Informants within the current study were influenced by these issues.

Many of the informants and their families used language associated with the military metaphor. For example, in describing her experience of going through the treatment regimes, in particular preparing for surgery, one informant comments:

**5.39** We had such a happy group and we went through together. I mean we were all facing — possible death, and some of us did die, — *I guess it was like going to war. We didn't know what was ahead of us but we had to go on. There was no going back.* [Emphasis added] (Doris, 1492-496)

The war analogy and its associated language and belief in the notion of the fighting spirit is so entrenched in the common sense discourse about cancer that a major belief is that individual will only survive if they actively engage in fighting the ‘enemy’ – cancer. One informant actually makes the statement:

**5.40** ... cancer patients — *they don't survive — unless they really fight.* [Emphasis added] (Martha, 1275-276)



Another informant, in talking about other patients in hospital makes the comment:

**5.41** I look at other people in here and I think, ‘They really don’t try to help themselves’, you know, *if you really want to live you’ll fight it*. (Sue, l 479-481)  
[Emphasis added]

In her use of the military metaphor, Sue is again demonstrating her desire to separate herself from the remaining patients who are the unhealthy ‘other’. She perceives all the other patients as lacking in the ‘will to fight’. In this way she colludes with the strongly held belief of the ‘healthy’ members of society that illness is caused through lack of willpower and, therefore, brought on by individuals’ own actions, or lack of action. The corollary to the belief expressed in the previous extract is that giving up the ‘fight’ means that death will rapidly ensue. For example, one informant describes the situation of another patient who had shared the same ward during her hospitalisation. The individual’s death was attributed to ‘giving up the fight’ rather than the accumulated effects of the cancer:

**5.42** We had one lady, just this time that I was in — she died — and she gave up. You could tell. She was in a lot of pain — uhm — ... you could literally tell the day *she gave up trying to fight it*. Uhm — it was a Tuesday morning and she had a cup of tea and she lost it — and just the look on her face — I knew damn well she wasn’t going to survive. Two days later she was dead.  
[Emphasis added] (Betty, l 1346-1357)

The implication in this extract is that if this patient had continued to ‘fight’, rather than ‘surrender’, she would still be alive. This is another example of the implicit belief that responsibility for developing cancer and regaining health rests with the patient. However, in the incident described in the above extract the implicit belief that the patient only died because she gave up the fight is in direct conflict with medical understanding concerning the functioning of the physical body. If cancer continues to spread, physical functions deteriorate and eventually succumb to the disease. Once life sustaining functions are damaged beyond a certain point death ensues.

Another important point, that is evident in the above extract from Betty’s narrative, is the fact that Betty is a qualified nurse. As such she is aware of the relevant medical knowledge concerning the fact that in some instances the progress of cancer overwhelms the physical functions of the body. Throughout her narrative Betty refers to her nursing background and medical knowledge. As these times Betty’s self-image as a nurse dominates her interaction

with the interviewer. However, in the above extract it is obvious that Betty's dominant self-image as a cancer patient influences this particular interaction.

Informants also report that some of their family members use the military metaphor in discussing responses to cancer. For example, one informant states:

**5.43** He [husband] said to me last night, he said "Oh well, *this is another battle* we've got in our lives to get over .... We'll do it." [Emphasis added] (Sue, l 498)

Furthermore, individuals diagnosed with cancer are perceived as locked in mortal combat with a specific enemy – cancer. One informant, who had been originally diagnosed as having cancer in 1965, and who had thirty-two cancer-related operations over the next twenty-eight years, makes the comment:

**5.44** *I'm a fighter*, you know, *I just sort of fight on* and it doesn't matter how many times it comes back. [Emphasis added] (Josie, l 668-670)

Similarly, fighting cancer is implied in statements such as:

**5.45** I'm going to beat it. (Sue, l 698)

**5.46** I've got to beat it. I don't want it to beat me. I'm only sixty-two, I mean, I've got a few years yet I reckon. (Fred, l 284-287)

Family members also use the language of battle to encourage the individual living with cancer:

**5.47** My daughter, the eldest one ... she kept saying, "You're strong. *You fight it. You go on.*" [Emphasis added] (Martha, l 178-180)

Informants also report that this battle theme, and the notion of the patient and medical team as 'allies' in this conflict, is reflected in the terminology used within the medical discourse about cancer. For example:

**5.48** The doctors talked to me yesterday. They were so positive — about it — tapped me on the back and said "*We're going to beat it. We've beaten it so far.*" [Emphasis added] (Sue, l 874-876)

**5.49** ... but they wanted to do all this treatment. They said to me that *they can kill* [the cancer], — because it's spread through my lymph glands and with all this treatment [chemotherapy] they — *it can kill* what's spread out. [Emphasis added] (Sue, l 306-310)

Another belief within the common sense discourse of cancer is that certain situations impede or encourage their ability to ‘combat’ the cancer:

**5.50** I was the sickest I’ve ever been I wasn’t giving up. No way was I going to give up, but — uhm — I was so weak — that — *I couldn’t fight very well* and that scared me. [Emphasis added] (Betty, l 1260-1263)

Related to the military metaphor is the discourse of hope which dominates cancer in modern western societies (Lupton 1994a).

### **The discourse of hope, bravery and self-images,**

The discourse of hope postulates that ‘winning’ the war against cancer is intimately linked to having a positive attitude to getting better. People with cancer are lauded if they never appear to allow themselves to ‘give in’ to the disease but respond with ‘bravery’. Lupton (1994a) suggests that the individual quickly learns that to despair or lose hope are discouraged as strategies of dealing with cancer. However, this external ‘pressure’ to display courage can be paralleled by individuals’ self-images developed prior to their cancer experience. For example, one informant describes the emotion she experiences on occasions:

**5.51** Some days I wasn’t [tough] and it disgusted me. And I’d sit there and say “Oh for God’s sake listen to meself [sic]. Don’t be such a wimp. Other people can do it. You can. Don’t sit there and wimp out” ... [but] it’s a fear of not being what I expect to be, you know, not being tough enough, not being brave enough to face it — better than being a coward ... it’s a fear that I’m not going to be able to — uhm — face the next bit. (Betty, l 1416-1427)

This extract demonstrates the complex interaction between two important issues, namely the influence of pre-existing self-images on interaction with current experiences and the common sense discourse practice of avoidance. Implicit in this extract is Betty’s fear that if she gets upset her behaviour will not be congruent with the self-image that she had previously developed through interaction with her family of origin. In interaction during her illness experience Betty is still greatly influenced by her self-image developed in the rough and tumble of her early life growing up with brothers:

**5.52** I’ve always prided myself on having more guts than brains [laughs] — being tough — I grew up with two brothers. You couldn’t let them see that you were weak [laughs] because they’d rounce all over you — and I’ve always prided myself on being able to deal with anything and being tough and being strong and all the rest of it. (Betty, l 1377-1391)

This self-image of being tough enough to take on any experience is so important for Betty that it influences her responses to her illness experiences. She responds to difficult situations with her 'tough, in control' image: a point not understood by nursing staff who encourage her to "have a good cry". Betty recalls an incident with the stomal therapist who approached her one day saying:

**5.53** "Having a bad day are we?" She must take one look at your face and know that your having a bad day. And she says, "Well why don't you just cry and get it over and done with? What are you holding it back for?" And I said, "'cause I don't want to make a fool of myself [sic]". "Well that's the stupidest thing I've ever heard of" she said to me "who cares if you make a fool of yourself? If anyone tells you you're acting like a fool I'll thump 'em for you." And she'd just close the curtains and say, "Here you are", give you a box of tissues and say, "Right. Have a good cry. I'll just sit here and look like a silly person and do my paper work while your having it"

**Interviewer:** So how do you normally react to those situations?

**Betty:** Very stoically. Generally I just keep it to myself until I can't do it any more and that's it, I get mad. (Betty, 1977-999)

In this extract Betty states her reasons for not crying - not wanting to make a fool of herself by not living up to her self-image as a tough, gutsy person. The stomal therapist not only fails to appreciate this situation and, through the use of humour, actually denigrates, albeit unwittingly, Betty's self-image, but also fails to hear Betty's initial emotional reaction - anger at her current situation. In this situation the stomal therapist does not take on the role of patient and use this knowledge in her interaction with Betty. Instead, she appears to take on the patient role as it is perceived by the professional discourse of cancer. In doing so, the stomal therapist imposes her 'reality' and understanding of the situation by encouraging Betty to "have a good cry" and get it out of her system. Unfortunately for Betty, crying is not what she needed to do at this point. Rather she needed to have her anger acknowledged and, if necessary, its open expression accepted. In turn, this may have led Betty to explore exactly what she was angry about (possibly the fact that she did not seek a second opinion despite knowing that the vaginal discharge she experienced for several months was a symptom of something seriously wrong, see extract 7.3, page 181).

Betty also speaks of her need for bravery when she was told by the oncologist that after the last test results he was unable to confirm that she would survive. When asked how that affected her Betty's response is:

**5.54** I don't know 'cause at the time I was having to pacify ... [husband] who was about to lose his bundle and the kids were there — I had to ask the kids to go somewhere else — you know, it was like — it was happening to somebody else — it wasn't happening to me — 'cause I had to be brave ... and I got one of the nurses to take the kids downstairs and then — ... [husband] couldn't take it and he took off. Just left me sitting there by myself — and then ... [oncologist] nicked off 'cause he couldn't cope — so I was just sitting there all by my lonesome feeling like — “Gee, you know, — like it's happening to me people. You're supposed to be here holding my hand [laughs] I'm the patient — get back here — somebody come and hold my hand” — [stops laughing] Nobody came. Not even the nursing staff — It was like they knew — that really bad news had been told and they didn't want to get involved, 'cause they can't cope either. (Betty, 1931-954)

This extract also demonstrates not only the disruption of social relations that occurs during serious illness but also the impact this has on the individual. Again it is not the sick individual who interrupts these social relations but rather the healthy members of society who do not provide the necessary emotional support for the individual. Betty is fully aware of why her husband and the oncologist leave her and why staff members do not approach her. She has been able to take on the role of carer or person relaying 'bad news'. Although Betty realises that it is their inability to cope with the situation it does not provide her with the emotional support she so desperately needs at the time: someone to simply stay with her and “hold my hand”. In a variation of the practice of avoidance of highly emotional experiences, healthy members of society (in this situation Betty's husband, the oncologist and nursing staff) are unable, for whatever reason, to take on the cancer patient's role and appreciate the need for appropriate emotional support and assess when it is most needed. The impact this has for the individual with cancer is discussed in Chapter Seven.

#### **“I was looking positive all the time”**

Another treatment related assumption is the necessity for maintaining a positive attitude at all times during the illness experience. There is an emphasis on strength of will that argues that if an individual has enough willpower (based on hope, individuality and fighting spirit) then the course of the disease within the body will be changed (Good, Good, Schaffer & Lind 1990; Lupton 1994a). Informants in the current study also demonstrate the influence

of this belief. For example, in discussing his attitude toward his cancer experience Fred recalls:

**5.55** I was looking positive all the time ... I was always thinking positive, you know, I felt bloody shocking 'though at some stages, you know, some stages of the game — ahhh — I felt bad about things — about the whole business — but like I say ... I was just confident in me [sic] own heart ... that I'd get through it ... I tried to think positive most — most of the time. (Fred, l 276; 530-564)

Implicit in this extract is the dilemma facing individuals with cancer. They are supposed to maintain a positive attitude at all times and if they do not they are implicitly accused of being weak willed and failing themselves and everyone else. The individual is again blamed for not only 'allowing' themselves to develop cancer, but also for not having enough fighting spirit to regain their health.

Similarly, another informant indicates that she is influenced by the common sense discourse belief that maintaining a positive attitude is important in successfully fighting cancer. She makes the comment:

**5.56** I'm mad ... very angry. That's the only way that's keeping me — keeping me good I think — keeping me positive thinking. (Sue, l 122-141)

This informant is reacting to her interpretation of the discourse of hope and the expectations that the patient maintain a positive attitude even when she thinks other family members might not be so positive.

**5.57** Mum's depressing me ... [begins to cry] because she thinks — I think she thinks — uhm — it's going to come back again, I think — I feel — I think she thinks I'm not safe .... But if I keep thinking positive — she's the one who hasn't got it so — she hadn't got it. I've got it so. (Sue, l 918-946)

Again, this extract demonstrates Sue's conflict with her prior self-image as a healthy person and her current situation of being in hospital recovering from surgical treatment for a life-threatening form of cancer.

The influence of the belief in maintaining a positive attitude is indicated by another informant, who reports the words of an influential alternative therapist:

**5.58** It's like something Ian Gawler once said to me, he said *the day that I decided that I was sick of being sick was the day I started my recovery*. [Emphasis added] (Jan, l 1331-1332)

Again, in this extract is support for the implicit belief that patients are responsible for their own health status and, in particular, recovery from the disease.

In some instances the importance of a positive attitude is implied rather than stated openly. For example, in describing her response to the initial diagnosis of cancer of the clitoris one informant said:

**5.59** I thought, "Well there are two ways out of this. I either die — or I get better, and *I don't choose to die so I'm going to get better*." [Emphasis added] (Doris, l 142-146)

Doris also indicates her positive response to the illness experience through the use of an analogy. In describing her experience in positive terms she states:

**5.60** It was as if somebody had wrapped me in a cocoon and I'd started down a tunnel or something that I had no way of getting out of, there was no — stepping sideways, I had to go to the end of the tunnel whatever it might be. And everything that happened from then on I accepted, ... I just accepted that it was going to be and it was going to be alright at the end. (Doris, l 173-183)

Other informants provide further evidence of the belief that sufficient willpower would influence the growth of the cancer. In discussing her prognosis, soon after undergoing surgical treatment for her cancer, one informant indicates that the doctors had informed her that the cancer could grow back again. In response to the doctor's comment she is trying to convince herself of the common sense discourse belief:

**5.61** I don't want it to. It's all in your mind. I think it is, don't you? Well I think it is — they say that if you think about it all the time that it will grow. (Sue, l 686-689)

This example also indicates the tension between conflicting beliefs within the common sense discourse about cancer. One belief is that individuals with cancer are supposed to maintain a positive attitude about the disease and their illness experience. The opposing belief is that thinking about the cancer all the time will cause it to grow. For this informant, interacting with these conflicting beliefs creates considerable confusion, tension and sense of guilt. Individuals are caught in a double bind. They need to think positively about their

cancer but that requires constant thinking about the disease. However, constantly thinking about the cancer supposedly causes it to grow. This point is discussed in greater detail in the section *The influence of the discourse of hope: A case study*, page 183.

The outcome of this need to be so positive all the time is expressed by one informant who indicates that she was:

**5.62** ... having to be so positive that you are blocking out any of the other side of it ... the fear was there [previously] but I kept pushing it away and saying “No”. Now I need to look at it and find out what it is. (Jan, l 471-475)

During her initial interaction with the diagnosis of cancer Jan takes the attitude of others into her imagination then chooses to respond in specific ways. In particular, she accepts the common sense discourse belief in the need for people with cancer to maintain a positive attitude at all times. Jan acknowledges that maintaining this positive attitude required her “blocking out any of the other side of it”. Effectively, what Jan indicates is that she was choosing partial interaction with her experience. She also acknowledges that she was aware of her fear but kept “pushing it away”. Jan’s choice of responding positively is also partly due to her fear of being “out of control”. As a consequence of these choices Jan was not able to engage in the process of reconceptualising her self-image. However, facing her fear was, for Jan, a way of engaging in the process of developing a more appropriate self-image that subsequently enables her to cope more effectively with her illness experience and be “at peace”.

### **Future outcome**

Another strongly held belief within the common sense discourse about cancer is that cancer is associated with severe, prolonged pain and inevitably results in a painful death. This belief is either openly stated or implied in comments made by informants. It can be made at any time during the illness experience whenever thoughts about the future and possible progression of the disease occur. For example, in a general discussion about cancer, one informant makes the comment:

**5.63** They suffer a lot — women with cancer — that die from cancer have a lot of pain and a lot of suffering ... that terrible agonising pain before they die ... people die in pain. (Josie, l 1496-1534)



Informants in the current study provide a range of examples of implicit statements supporting the belief about the pain associated with cancer and cancer-related deaths. These are frequently provided as individuals discuss their own beliefs about their future in light of their cancer experience. For example, one informant believes that because she has cancer she would experience severe pain at some time in the future:

**5.64** It's the fear of seeing the pain they go through ... I'm a coward with pain. *I don't want to go through that pain.* That's what I don't want to go through. [Emphasis added] (Doris, 1901-1913)

Also demonstrated within this comment is the strength and pervasiveness of the military metaphor. Doris attributes her inability to cope with pain to her being a "coward". The implication being that if she were 'brave enough' she would be able to accept any pain as part of the normal battle against cancer and 'take it in her stride' without complaint.

One informant returns to this issue a number of times during the interview:

**5.65** I don't want to die in pain ... I'm afraid of going through all the agony ... I am scared of dying, but only scared of dying in — pain. (Betty, 1301; 1319; 1522)

This association of cancer with pain is also linked to the belief that a 'dignified' death is one that is pain free. There is a belief that the individual's dignity and hard-won adult status is weakened by pain (Le Shan, 1983). As will be demonstrated in Chapter Eight, this belief is also similar for individuals with HIV/AIDS and indicates that the common sense discourse about life-threatening illnesses is also informed by the discourses about dying and death. The assumptions of these discourses, that have particular relevance to the discourse about cancer, are that death is a painful event and there are preferred ways of dying. One informant openly states the connection between her fear of pain and wanting to die with dignity:

**5.66** I really fear — not dying with dignity. In other words, having pain. (Jan, 12207-2208)

Another informant provides further support for the belief that a dignified death is one that is pain free. She describes the recent death of another patient, whom she had met during previous periods of treatment in hospital:

**5.67** She just went to sleep — and she died nicely — where other people die in pain — and when I say die with dignity I mean die nicely, just go to sleep. (Josie, 1532-1535)

This example also demonstrates the overlap between the common sense discourses about cancer, dying and death. Josie uses the common belief that death is like going to sleep or is a sleep like state from which individuals 'awake' in another 'world' or 'existence'.

## **Summary**

The common sense discourse of cancer, as a perspective, provides members of the lay community with a definition of the situation concerning cancer. The elements of this discourse provide a configuration of meaning that enables healthy individuals to organise their own conduct, and their expectations of others, in relation to this definition. This configuration of meaning also shapes beliefs and expectations about how the disease progresses and how the consequent illness experience is likely to unfold. Prior to their own diagnosis, individuals come to know and understand the self-evident routines of everyday life with cancer through this common sense discourse. When confronted with their own diagnosis of cancer, individuals rely on this discourse to organise their conduct, their expectations of others and their interaction with personally unfamiliar disease-related social objects. However, in confronting their own diagnosis, individuals are challenged by a number of elements of the common sense discourse that raise dilemmas for them: cancer means death, but, at the time, they do not perceive themselves as dying; cancer means a painful experience and agonising death, but they are not sure whether they will be able to cope with the intensity of the pain; cancer means avoidance by others, but they still require social support; beating cancer means fighting for life and being positive at all times, but sometimes they feel overwhelmed by their emotions. At the same time, these dilemmas challenge individuals to reconceptualise self-images: from healthy responsible person to 'irresponsible, unhealthy other'; from a living person to one facing their own mortality and impending death; from socially acceptable person to one who is stigmatised and frequently ostracised.

Despite advances in medical science that enables some forms of cancer to be cured, if diagnosed sufficiently early, the link between diagnosis of cancer and death is still strong

within the common sense discourse of cancer. This link is frequently expressed in the practice of some family and friends avoiding routine social interaction with individuals after their diagnosis. In turn, this creates a form of social death that reflects the disordering of routine social relations and increases the emotional burden for individuals. This perceived inability of some others to cope with the multiple meanings associated with a diagnosis of cancer, forces ill individuals to take on the role of 'carer'. To maintain social interaction and support from others (including some family members) individuals push their 'negative' emotions aside; they present a 'brave' or 'humourous' façade; they refrain from discussing their emotions or illness experiences. In essence, they disregard their personal thoughts and feelings, suggesting that what they are feeling must be wrong or inappropriate. Beliefs and practices within the common sense discourse of cancer convey explicit and implicit messages to the individual diagnosed with the disease about how they should respond to their illness experience. The sick individual must not only be able to confront the most emotionally difficult aspects of treatment and the prospect of their death with minimal support but also with courage and a positive attitude.

The common sense discourses of cancer and culpability have a powerful influence in ascribing 'responsibility' for developing cancer. In response to this situation individuals devote considerable time and emotional energy in trying to find a 'cause' for developing cancer. These reasons why people develop cancer range from contact with carcinogenic substances, being punished for some 'sin' of commission or omission, and being 'sent' the experience for personal development. These 'causes' of cancer serve two purposes. Firstly, they contribute to making the seriously ill individual responsible for their disease, their illness experience and their ultimate recovery. Secondly, these reasons for cancer development 'safeguard' the healthy members of society by reinforcing the belief that only irresponsible members of the community develop cancer because they fail to take proper care of their health or they do not have sufficient willpower to maintain a healthy lifestyle. The causes of cancer also serve to create a distance between the healthy members of society and the irresponsible, unhealthy 'other', decrease the amount of emotional and practical support for the individual and increase their tension and loneliness. Furthermore, application of the military metaphor to the experience of cancer further obligates sick individuals to take responsibility for their recovery, to face the disease with bravery and

equanimity and not display too much emotion. This places further emotional burden on individuals living with cancer.

In essence, beliefs and practices within the common sense discourse of cancer promote dual standards. On the one hand the patient must be brave, maintain the 'fight' against the enemy, be positive at all times and avoid stress by dealing with their emotional issues as they arise. However, in dealing with these strong emotions individuals must not become 'too upset' or 'too irrational'. On the other hand healthy members of society are able to use avoidance as a way of coping with the intense emotions without censure from beliefs and practices within the common sense discourse. The use of humour also has a duality of purpose. Firstly, it acts as a coping and distancing mechanism for healthy members of society by sending the implicit message that the person does not want to hear more of the sick individual's experience. Secondly it denigrates the severity of the individual's experience of cancer by implying that it is not serious enough to warrant further discussion.

At the same time individuals are interacting with members of the lay community, who use the common sense discourse to provide meaning to cancer, they begin interacting with members of the medical community. During this new interaction, individuals are introduced to a new perspective (the medical discourse) and new ways of defining cancer-related social objects. How individuals interact with this different perspective and how it influences their experience of illness is the focus of the next chapter.