

Chapter 7

Understanding How Individuals With Life-threatening Cancer Construct Their Discourse

Introduction

At a social level, the common sense discourse provides members of the general community with ways of knowing and talking about the world of cancer, as a life-threatening illness. Similarly, the medical discourse provides members of the medical profession with ways to describe, categorise and give meaning to cancer as a disease. However, as was demonstrated in Chapter Six, through interaction with health care professionals patients construct their own interpretation of the medical discourse.

As their illness experience progresses individuals become aware that some of their personal issues and experiences are not in common with either discourse. For example, there are times when individuals lose hope, feel overwhelming despair or extreme fear or anxiety and want to quit their 'fight' against the disease. At these times they perceive that neither discourse encourages open expression of these strong emotions. More importantly, beliefs within the discourse of hope actively discourage the expression of despair and losing hope as coping strategies (Lupton 1994a). Patients also perceive that both discourses incorporate the belief that the expression of strong emotions is negative and counterproductive to the restoration of good health. Furthermore, the practice of some family members and friends in avoiding the individual with cancer leads them to believe that the community does not want to discuss emotional issues. However, there are times when individuals living with a life-threatening form of cancer do wish to discuss these issues. Patients also perceive that the medical discourse focuses on treatment and cure at the expense of the individual's subjective and emotional experiences. Nevertheless, there are times when patients want to obtain medical information that is not cure specific, for example, discussing details about their experience of treatment side effects or their emotional response to the illness experience. Patients perceive that these issues are given minimal focus within the medical discourse.

The importance individuals attribute to these marginalised issues is demonstrated by the fact that they develop their own way of discussing these issues with selected fellow patients and anyone else who will listen: in essence an ‘experiential’ discourse is developed. Furthermore, despite their experience of not being able to discuss their emotional issues within the framework of either discourse, patients continue to demonstrate their need to do so. This is apparent in their illness narratives by their oblique or symbolic reference to these issues. When these indirect or symbolic references are acknowledged individuals often readily discuss the subjective meaning of their illness experience.

The purpose of this chapter is to identify how informants respond to those aspects of the common sense and medical discourses about life-threatening cancer that were identified in Chapters Five and Six as producing dilemmas for individuals. The first section will identify how informants respond to their experience in ways that are defined by the discourse of hope which is common across both the common sense and medical discourses about cancer. At the same time it will illustrate how informants provide indicators that their illness experience is not adequately described or given meaning by elements of either discourse. The second section will identify some aspects of the experiential discourse. That is, it will identify some elements of how patients describe, categorise and give meaning to their experience of living with a life-threatening form of cancer. Many of the issues raised in Chapters Five and Six trigger individuals to think about their future. From a medical perspective, the discourse of grief, and in particular the discourse of anticipatory grief, describes, categorises and gives meaning to patients thoughts, behaviour and emotions in the situation where individuals are confronted with the expectation that they will encounter a significant loss. This chapter focuses on how patients react to thoughts about their future rather than attempting to identify all aspects of this experiential discourse. It will also demonstrate the extent of the influence of the discourse of hope on individuals’ responses to their illness experience.

Responding in ways defined by dominant discourses

When individuals either suspect, or are informed, that they have cancer they begin a journey through personally uncharted territory. Their only guide to making meaning of their new experience is the common sense discourse of cancer and a number of related discourses (e.g., discourses of hope, dying, death, grief, pain, suffering) that dominate the

way the community describe and categorise the experience of living with a life-threatening form of cancer. Beliefs and practices within these discourses provide a definition of the situation and a configuration of meaning that are used by individuals to organise their action and the expectation of how others will act. Simultaneously, these beliefs and practices have the effect of disenfranchising the expression of other experiences and behaviours. That is, the individual living with a life-threatening form of cancer is expected to respond and discuss their experiences within socially acceptable boundaries and refrain from acting in ways that are not socially sanctioned or supported. For example, within the discourse of hope, optimism, a coping attitude, cheerfulness and strength are endorsed. Alternatively, giving in, cowardice, fear and 'denial' are not considered socially acceptable ways of dealing with life-threatening forms of cancer (Lupton 1994a). As they progress through the diagnostic and treatment processes individuals come into contact with, and subsequently interpret aspects of the medical discourse about cancer. In response to the socially prescribed behaviours and values within these discourses, individuals initially construct their illness narrative in a form that they perceive is acceptable to the personal or professional background of their immediate audience. That is, they take on the role of a community member or health care professional, who has not had cancer, and discuss their experiences using language and concepts that, based on previous experience, they believe the current listener will comprehend and accept.

Disclosure of experiences is influenced by two major issues. Firstly, whether the individual perceives that the listener is interested in hearing the patient's subjective experience. This assessment is based on whether or not appropriate verbal and non-verbal cues have been given and responded to. Secondly, whether the individual believes that the current environment is one in which their issues and emotional responses are likely to be accepted rather than devalued. For example, one informant, sensitive to her friends' inability to visit her personally, because of her appearance during treatment and their reluctance to discuss her cancer experiences, still required their support. Therefore, she suggested that they ring her in lieu of personal visits. She makes the comment:

7.1 A couple of my friends couldn't bear to come and visit me — when I came home and I was a little bit sad about that — but then again, *when I looked in the mirror I look 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 to them, "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, even 'though they — they couldn't bear to come and see me ... *But we didn't talk about cancer*, you know. But we would talk about the kids and all this, that, and the other, and -- whatever else, you know. [Emphasis added] (Dulcie, 1498-515)

In this extract Dulcie demonstrates the process of role taking. She takes on the perspective of her friends and believes they would be shocked by her physical appearance. She then rationalises her perception of their reaction by saying she did not want them to see her like that. To maintain social interaction Dulcie suggests that her friends telephone her. She also purposely avoids discussion of her illness experience: a strategy with which her friends apparently collude.

Structure of illness narrative

At the outset of their narrative, individuals describe their emotional reactions and experiences in the positive framework of the discourses of hope and personal culpability and the related military metaphor (see Chapter Five). That is, maintaining a positive, personally responsible attitude and doing everything possible in order to defeat the invasive enemy, cancer. A very clear example is provided by one informant who began her narrative by describing her diagnostic experiences of several months duration. Betty was referred to a gynaecologist after receiving inconclusive results from several Pap smears. The gynaecologist “didn't pay much attention to the abnormal cells” as he was “more interested” in a “hernia between the bladder and the vagina”. Eventually another Pap smear was completed and the results were again inconclusive because of “too much blood in the specimen”. The gynaecologist diagnosed “cervical erosion”. A second Pap smear results stated “pre-cancerous cells - repeat in three weeks time”. In the mean time, Betty was booked into a local hospital to have an “anterior repair job done”. Betty initially presents herself in a positive and responsible way by describing her experiences in terms that indicate she was assertive with the gynaecologist and did all she could to have her medical condition thoroughly investigated:

7.2 And I said to him at the time, I said, “While you're there, why don't you do a biopsy — of the cervix?” and he said, “Oh no. It's OK. It's just cervical erosion.” I said, “Yeah, but for my peace of mind I'd like a biopsy done,” you know, “it doesn't take much. I mean, you're there anyway, just do it.” And — ahhh — he didn't do it. — Forgot. — ahhh — So since that operation — oh and I had a really horrific discharge that smelt terrible. I mean it was embarrassing to go out. You couldn't go anywhere because this thing just stunk. It was gross.

And he kept saying it was cervical erosion. So I put up with it for a while, but then in December it just got worse, and I thought, “Oh no, there’s definitely something wrong,” you know, “this just can’t be real”, and I kept hounding him. I kept going back every week and saying to him, you know, like, “Do something. I mean, this is driving me crazy.” And — uhm — but he didn’t do anything until February when I really did my cruet and I said, “Look, we’re doing a biopsy and we’re going to do something about it. We’re going to cauterise the cervix. Even if you amputate the cervix,” I said, “I’m sick and tired of this. Get rid of it. Even if you have to do a hysterectomy, I don’t care.” ... and I kept saying to him, you know, “If I didn’t know better I’d say I had cancer” and he kept saying, “No, no, it’s just cervical erosion. They’re similar”. And I’d say to him, “Well let’s do a biopsy and make sure”. And — I don’t know how but he just kept foobing it off, you know, “Oh well”, you know, “we’ll try this first and see if it works.” Like palliative care — But to me it was wrong. I mean, he should have done the damned biopsy. It was as simple as the nose on his face. (Betty, 147-66; 272-282)

Despite being unsatisfied with the gynaecologist’s diagnosis Betty did not talk about seeking a second opinion. It is not until toward the end of her narrative, when asked whether there was anything else that she thought the interviewer needed to know to understand her experience, that Betty explains why she did not seek a second opinion. Although she is feeling more at ease with the interview by this time, Betty begins volunteering this information in terms acceptable within the discourses of hope and personal culpability - anger at herself for remaining with the gynaecologist despite ‘knowing’ that something was wrong. Betty is still ‘feeling her way’ with disclosure of sensitive information. It is obvious that this is a very personal issue for Betty and she is still not entirely sure how the interviewer will respond to her information. Initially, she does not openly ‘claim’ her actions and couches them in terms of an interaction with another patient. It is only after the other patient openly identifies Betty’s reason for not seeking a second opinion, and the interviewer asks a non-judgmental clarifying question, that Betty accepts her own motivation - fear of the second opinion proving that cancer was present:

7.3 Betty: There’s anger at yourself for — not — my biggest anger is and — and it’s there all the time — why didn’t I do something about it. If I didn’t — if I knew there was something wrong, and I did, why the hell did I persist with that idiot [gynaecologist]. Why didn’t I go somewhere else and get a second opinion — and that’s my biggest thing I mean, it’s all right to look back in hindsight and say I should have done that — and kick yourself for not doing it — but this is the whole thing — why didn’t I? — and I can’t understand it, you know, and then — one of my — the people that I’ve met in hospital, her name’s ..., she says, “Oh don’t be stupid!” She gave me a thump and she said, “You were scared! You didn’t want the second opinion! You stayed with him because he

gave you a diagnosis of cervical erosion, and you were too scared to go and get the other one!”

Interviewer: How accurate was that?

Betty: Dead accurate! And she said, “And when you did find out you had it, you didn’t get as upset as anybody else because you thought ‘I knew it!’” ... “You didn’t want a second opinion because subconsciously you didn’t want to know the answer”, and she said, “don’t panic we’ve all been there. We’ve all done it”, she said, “including ‘moi!’” She says [sic], “I didn’t go and get a second opinion because I liked what he was saying — until it was too late.” But that was the biggest thing and I still feel it; mad at myself for not having the guts to get a second opinion, see, and what was stopping me? Fear! — of that second opinion proving that I did have it [cancer]. (Betty, l 2065-2133; 2163-2171)

The issue of the strength of beliefs within the discourse of hope effecting the disclosure of other sensitive issues will be detailed as other examples arise later in the chapter (see discussion of extracts **7.31** page 195, **7.40** page 204, extract **7.56** page 213 and section on Anxiety about separation, page 221).

Another informant describes her efforts to remain positive and fight the cancer. Jan acknowledges that she had to actively push her emotional response aside in her attempts to maintain a positive attitude:

7.4 I could feel the fear at that point. [Previously] the fear was there but I kept pushing it away and saying no ... *having to be so positive that you are blocking out any of the other side of it* ... It was a very positive time. It was like I’m going to beat this — If anything, there’s an arrogance about it too. *Again, it was like the fear was being pushed aside ... It was a conscious pushing ... It was like — I’m not going to let this beat me — I’m going to do everything I can to stop it — I’m going to be positive about this — and — again, sort of, pushing the feelings aside.* [Emphasis added] (Jan, l 470-475; 974-991)

Considerable tension and dissonance is created, particularly for individuals recently diagnosed with life-threatening cancer, as they struggle to simultaneously cope with the strength of their personal emotional response and live up to the expectations within the discourse of hope and implicit in the military metaphor. This tension still exists for individuals receiving treatment, or post-treatment check-ups. However, individuals make attempts to raise these issues with whomever will listen. As they proceed through the treatment process friendship and support networks develop with fellow patients. Discussions with these newfound friends often centre on common experiences that are marginalised by both discourses.

Diagnosis

Individuals who have been recently diagnosed experience considerable dissonance that arises from the conflict between the strength of their emotional reaction to their own cancer diagnosis and their perception of the demands of other with whom they are engaged in social interaction. That is, patients perceive that neither the common sense nor medical discourse provides avenues for families to discuss or resolve, among themselves, their strong emotional reactions. The fact that, at the time of diagnosis, individuals have not had the opportunity to meet and develop friendship networks with other patients and learn that they, too, frequently experience similar emotional responses, further aggravates this situation. Family members who are also influenced by the discourse of hope and the military metaphor to remain positive at all times may add to the tension for patients. In some instances individuals seek to avoid engaging in social interaction with other patients with cancer. This situation of conflict and turmoil is best clarified by the use of a case study.

The influence of the discourse of hope: A case study

Sue, who was interviewed in hospital a week after surgery (and three weeks after diagnosis), demonstrates this struggle and resultant turmoil throughout her narrative. Her statements are often disjointed, her thoughts fragmented, her speech is rapid, she frequently contradicts statements made earlier in the narrative, she routinely projects her own negative thoughts onto other patients or her family members, she regularly sheds tears throughout the narrative and she attempts to distance herself from other patients. Initially, she attempts to respond 'bravely' and use terms of the military metaphor in an attempt to convey her commitment to fight the cancer. She states that the diagnosis of cancer:

7.5 ... didn't really worry me 'cause like — you know — everyone told me that they're so good these days with cancer they can fix you and everything, so I really didn't — didn't bother me — well I don't know, I probably didn't think — ahhh — you know, — I probably didn't think it was going to be cancer. It still hasn't worried me yet because *I still believe that it's not going to beat me*, so — that's the way I feel — even 'though I've got the evilest you can get apparently — *I still say it's not going to beat me*. [Emphasis added] (Sue, 148-68)

Still influenced by the military metaphor, Sue expresses her emotional reaction in an acceptable form: apparent anger at the cancer disturbing her life; anger that can be directed into fighting the cancer:

7.6 I'm mad about it. I'm mad. I didn't want this — at all. 'Cause I've got two young children — my youngest is fourteen months old so they've been mucked up and — I've been mucked up. I'm not really worried about myself. I just want to hurry up and get better and get home ... I just keep thinking positive and — think, 'Hurry up and do all these terrible things to me and then I can get home'. (Sue, l 72-87)

On the surface this extract seems to be about anger. However, when taken in conjunction with other statements it appears that Sue is experiencing considerable fear: fear that arises because she is influenced by the belief within the common sense discourse that equates cancer with death (see extract **5.17** page 118); and fear because she remembers her father's cancer treatment, over a nine year period, and his death some three years prior to the interview. Sue thinks that she, too, will die as a result of cancer:

7.7 I know that ... [named treatment center] — it's horrible over there. My Dad had it [said softly] ... he had major major operations. He went through hell to stay alive. In the end they wanted to do one more and he just said no. He'd had enough. They'd been — ohhh — horrible operations he went through. And I watched him go through hell too ... Why did I have to get this? ... I just thought I was going to die. (Sue, l 198-271)

Sue is also upset and scared at the thought of her children having to go through what she went through with her father. Fear for herself is also evident in Sue's narrative but she is unable to articulate it specifically:

7.8 My youngest is only fourteen months. And I just didn't want them to go through what I went through [starts to cry] — it's not nice ... *And I don't want to die.* I just want to get better. *I'm too young.* I'm only twenty-four, you know. Why couldn't I have been fifty-four? It wouldn't have been so bad, you know. I've got a lot of life to lead yet. *And I don't want to die* [still crying]. [Emphasis added] (Sue, l 273-295)

In this extract Sue is talking about not wanting her children to have the same experience as she did with her father. This prompts her to think of his death and become frightened at the prospect of her own death. The emphasized statements, along with the tears and vocal tone in which they were delivered, indicate that she is frightened for herself and her future.

Sue's tension, between her perception of the expected responses within the common sense discourse, the medical discourse and the discourse of hope and her own emotional response, is so great that she is unable to acknowledge how she is feeling. Instead she projects her own feelings onto other patients within the ward before acknowledging that she, too, is upset:

7.9 It's hard being in here [hospital] — 'cause everybody's depressing [sic] — I — you know, they're worrying about having to have chemo and — like I've got to have chemo and radio — uhm — like I've got to have radio for six weeks, for five days a week treatment — and — uhm — but you've just got to do it. If you don't want to die you do these things. Like they got all me [sic] cancer out of me what was there. The operation was a success, so I — they just want to do this just in case this is — my chances are pretty good, I think ... It's just that — they got everything out that was out [sic] of me. Um — and now I have to go and have chemo — I have to — I come back here Monday and have chemo for three days and then I have to — I go home for two weeks and then I'm back in ... [named hospital] for six weeks — five days a week getting treatment and then more chemo after that. You know, — I was just hoping — I could have just gone home. I thought they would have come and said, "We got it all out and you don't need anything and you can go home." That's what I was hoping — I knew — I was talking to the staff — I would have to have all this, and I don't know why I was so upset when I found out. I just thought — you know, I could go home and I didn't think it was going to be so bad. (Sue, l 150-190)

The tension is evident in this extract as Sue struggles with her attempts to maintain the positive attitude 'prescribed' within the discourse of hope and the military metaphor. Despite the obvious emotional turmoil she is experiencing, Sue attempts to maintain her composure and a 'positive' approach but has considerable difficulty. Sue responds in this way because she believes it is the 'correct' response. She rationalises the difficulties she experiences in remaining positive by claiming that it is being in hospital that makes it hard to remain positive. Sue initially says this is because of the other patients whom she tries to avoid by spending as much time as possible out of the ward, walking around the hospital corridors:

7.10 I look at other people in here and I think, "They don't try to help themselves," you know. If you really want to live you'll fight it. (Sue, l 479-481)

7.11 When I think positive — perhaps think positive — because I want to get out of here — Everybody's so depressing [sic] — see it's the first time they've ever had anything in their families like things — like depressing things — I'm used to it, I mean, — and I've been — I like to go out in the elevator and sit out and get out and get away from this whole area — and be myself again. It depresses me being in here — I just want to get out and go home — and just forget about

it ... just get me out of this place. I hate it — hate being in here ... well they [other patients] always say “What about cancer. What if I’m going to be sick?” You know, “What if I’m going to be sick and all that ... all they do in here is talk about it all the time — like I now that sounds silly — of course you’ve got to talk about it but, I mean, — I don’t want to talk about it. (Sue, l 757-808)

The above narrative extract exemplifies a contributing factor to Sue’s current state of turmoil: the difficulty she is experiencing with her conception of self. Surgical treatment so quickly followed diagnosis that Sue has not had time to reconceptualise her self-image as a seriously ill person. Sue still does not perceive herself as a sick person and in no way does she consider herself in a similar situation to the other patients. To distance herself from the other patients, whom she perceives as ‘unhealthy others’ she projects her own negative attitudes onto the other patients: they are depressed; they do not try to help themselves; they haven’t experienced difficulties like she has; and all they want to do is talk about their cancer. This situation is augmented by her fear of dying. To reconceptualise her self-image as a seriously ill person Sue must also confront the very real possibility of her own mortality and impending death.

In her attempts to remain positive, and separate herself from the negative image of unhealthy others, Sue also projects onto her mother her own negative thoughts about the cancer returning. She begins to blame her mother for depressing her. This is also in accordance with the discourse of personal culpability. Sue is conveying the impression that she is doing everything possible to fight the cancer and it is others who are unable to maintain the required positive attitude:

7.12 I feel I’m safe after that [chemo] but everybody else seems depressed still. And, you know, they’re depressing me. Mum’s depressing me. — I don’t know why she’s doing it — you think she should be happy for me — [begins to cry] because I think she thinks — um — it’s going to come up again, I think — I feel — I think she thinks I’m not safe and she’s always right — you know what I mean? (Sue, l 915-934)

Sue also attempts to convey the impression that members of her family are coping well with her cancer experience but again the turmoil she is experiencing is self evident. In response to a question asking how her mother is responding, Sue states:

7.13 Pretty bad. We’re arguing with each other a little bit, but that’s just normal — for us. She’s doing pretty good actually — too good. I don’t know how she does it. She’s a wonderful lady — you know, watch her husband die, then her son, and now this — her daughter — she’s been sad through the whole lot with

this. Like, you know, she's been through it all with Dad — and see I'm so positive about it — and I say to her “Why aren't you happy — with that news? — why aren't you happy?” and she just says, “Well I am.” But she won't show any — any happiness for me — I don't know why. (Sue, l 632-645)

Throughout the interview Sue continues to fluctuate between her attempts to maintain a positive attitude and expressing the emotions that she feels. Whenever she expresses a 'negative' opinion it is immediately followed by something positive. For example, in talking about wanting to be around when her children grew up Sue makes the comment:

7.14 There's not much I can do if I can't beat it, is there? — I just hope they [doctors] can. So far, so good though. (Sue, l 541-543)

Sue also experiences considerable tension created by a paradox within the discourse of hope: the belief that positive thinking and willpower will defeat the cancer and the belief that thinking about the cancer too much will cause it to grow. Initially she indicates that her anger at the cancer keeps her thinking positively:

7.15 [I'm] very angry. That's the only way what's keeping me — keeping me good I think — keeping me positive thinking. (Sue, l 133-141)

A little later in the interview, Sue demonstrates the continuing tension she is experiencing. Although being told by her doctor that the cancer may re-grow Sue did not think it would because:

7.16 It's all in your mind. I think it is, don't you? Well I think it is — they say if you think about it all the time that it will grow. (Sue, l 685-690)

In this extract Sue is attempting to convince herself that willpower will stop the growth of cancer. She attempts to enlist the support of the interviewer before making a positive statement about the efficacy of the power of positive thinking. However, she is then challenged by the paradox: The act of thinking positively about cancer implies that the individual must actively engage in thinking about the disease. In turn, thinking about the cancer will also cause it to grow.

At a later point in the interview Sue says that she does not want to think about the cancer because it reminds her that she might die:

7.17 I don't want it to sink in. It goes in one ear and out the other what the doctors tell me — 'cause I don't want to hear about it — I just want to block it all out — 'cause I was going to be told I was going to get better and that's — I don't

want to hear nothing [sic] else ... and I said, “Am I going to die?” and they said, “No.” So I said, “Oh well, that’s all right. That’s all I wanted to know.” You know, I wanted to know if I was going to die in six — you know, if people get cancer they die six months later and things like that, that’s all I wanted to know. (Sue, l 704-721; 884-897)

At another point she presents a ‘brave’ front saying that she is able to joke about her experience:

7.18 I’m not taking it seriously though ... Everyone is very serious; the doctors and everything, about it, and I just joke about it all the time — ’cause I don’t want to accept it. I don’t want to accept — you know, I’ve got it — I’ll go through all these things and that’s it, that’s — I don’t — I don’t want to think about it. You think about it and you get depressed — ’cause you might die. (Sue, l 1275-1297)

The considerable tension experienced by Sue is clearly evident throughout her narrative. She is obviously overwhelmed by her emotional response to her diagnosis of a life-threatening form of cancer. Sue is reassured temporarily by the doctors comments:

7.19 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. (Sue, l 874-878)

However, Sue is so caught up with her emotional turmoil that this reassurance does not last long. Analysis of Sue’s narrative reveals that much of its apparent disjointed nature can be attributed to two major dilemmas: the conflict between expressing her emotional reaction and trying to maintain a positive attitude as prescribed within the discourse of hope; and reconceptualising her self-image from a healthy person to one that has a life-threatening illness. Throughout her narrative Sue begins to make an emotional statement but, believing that she has to be positive all the time, then attempts to present a brave, fighting front. She also distances herself from the otherness of fellow patients at every opportunity.

Treatment

Individuals who have been living with a diagnosis of a life-threatening form of cancer for a longer period of time do not experience the same intensity of tension, as do recently diagnosed individuals. As they progress through treatment individuals learn that often family members or friends either have difficulty discussing certain issues concerning the illness experience or avoid them completely (see Chapter Five). As a result tension

develops between family members (e.g., see extract **5.33** page 127). Consequently, patients learn to discuss their experiences in ways that are appropriate to their audience (see discussion of extracts **7.1** page 179, **7.2** page 180).

Another example is provided by Doris who, at the outset of her narrative, describes her experience of preparing for surgical treatment by avoiding any reference to what might be classified as negative emotional descriptors. Instead she includes herself in a group of patients being prepared for surgery and, using the more socially acceptable positive imagery, describes the group as “happy”. This description implies that none of the group was experiencing any anxiety, fear, apprehension, nervousness or agitation at the prospect of surgery. At the same time, this informant acknowledges that they were all facing major surgery and possible death. Major surgery is normally a situation that is socially accepted as inducing some anxiety or worry (Janis 1974). Facing possible death is a situation in which strong feelings are not openly discussed:

7.20 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. (Doris, l 492-496)

Although discussing their experiences in socially acceptable, ‘public’ ways, patients demonstrate that they are not only prepared to discuss a variety of issues concerning their illness experience, but also that they have actually discussed sensitive issues among themselves. For example, in describing her experiences during a medical consultation (see extract **6.39** page 164) Dulcie reports how her concerns were minimalised by the oncologist remark. In response to his comment that she was the unlucky individual in two thousand patients that experienced that particular side effect, Dulcie demonstrates that she has discussed these issues with other patients. She knew of “three people ... who’ve got the same thing as me”.

Informants in the current study demonstrate their willingness to discuss a variety of issues relating to their illness experience by frequently providing oblique or symbolic references to the existence of different ‘private’ realities. These references are a class of social objects and may be either verbal or nonverbal.

Verbal symbols

In describing their illness experience informants frequently provide symbols in a verbal form that are intentionally used to point to the existence of a personal reality that differs from the public image being projected. Very clear examples of these direct symbols are given by informants in the current study. For example, when asked to identify the major issues concerning living with her life-threatening disease Doris begins by identifying, and justifying, the surgery that had been performed. She proceeds by providing some brief information on the incidence of her form of cancer before mitigating the emotional content of her message by making jokes, first about her daughter's response then about her own response. However, embedded within her narrative is an aside that symbolises that her public show of joviality, concerning the effects of surgical treatment, may not necessarily be congruent with her private reality. More medical information immediately follows the embedded aside. Then Doris again refers obliquely to her private reality. This second reference is couched in a form of emotional language that is restrained and socially acceptable. Nevertheless, it acts as an indicator that there is possibly more depth to Doris' response than already stated:

7.21 I had a vulvectomy. That means that I had cancer of the clitoris, which is very rare. It only happens thirty times a year in ... [named city] and usually in older women of seventy or eighty. My daughter tells me I'm old at fifty-three anyway, [said in jocular manner] and I laugh about it and I say, "Oh well, I'd decided not to use the equipment anymore, anyway." *But that's beside the point* [spoken very softly]. Ah, it was — they said when they did it, it was a fifty-fifty chance because it had gone into my lymph nodes and they don't — it was only miniscule, but they still didn't know how far it could have gone beyond there. So three times since I had it [surgery] nearly two years ago, *we've had a scare. It's getting less and less each time.* [Emphasis added] (Doris, 117-48)

In this extract Doris includes medical terminology, humour and detached, unemotional language to refer to intimate parts of her body. In contrast to the jocularity of the initial part of this extract, the important aside is delivered in a very softly spoken manner. A listener, who is educated in a discipline that focuses on reason, the rational and the objective, may be misled by some of the contents of this extract, and the way it is delivered, into thinking that Doris is coping well with the after-effects of surgery. As a consequence of focusing on these particular aspects of Doris' language, the listener may not detect the importance of the embedded aside. In fact, the tonal quality of Doris' voice changes so dramatically that some listeners actually may not hear the aside. However, when asked, "What's getting less

and less?” Doris responds with a comment, which has an emotional content, albeit delivered in a detached manner: fear that the cancer is spreading. This is followed by another socially acceptable response – a justification for her emotional reaction:

7.22 *The fear.* Every time there’s another lump or something else, they think — because you’re never really sure. [Emphasis added] (Doris, l 52-56)

A short time later in the interview Doris provides another example of discussing her experience in rational, logical, ‘public’ terms and embedding a symbol indicating an alternative private reality. She describes the events leading up to surgical treatment, her responses and an acknowledgement that, in hindsight, she had not personally prepared herself for the implications of surgery despite information provided by medical staff:

7.23 And I just accepted everything that happened and when they said they were going to have to operate and take it out — I don’t think I realised then what the implications were. I knew part of me would disappear, but I didn’t realise how much [voice begins to break] and how much I’d be disfigured. Um — I thought, ‘Well, that’s OK. People lose their breast and live through it — I mean, you can’t even see where I’m going to lose mine, and I’ve decided not to use it anyway anymore, so that will be all right [said humorously] so that’ll be all right.’ And that’s how I sort of approached it. *You do crumble after a while.* [Emphasis added] (Doris, l 191-206)

Doris’ choice of words to describe her reality also acts as an important symbol. She chooses “crumble” rather than ‘shattered’, ‘devastated’, ‘overwhelmed’ or ‘blown away’. The word “crumble” symbolises a gradual erosion of her ability to maintain her belief in remaining positive: A gradual erosion of her positive attitude. When the importance of her verbal symbol is acknowledged and she is asked what she meant by “crumble” Doris responds with a description of her subjective reality and meaning of the after-effects of surgery. This includes a comment that is in opposition to the tenets of the military metaphor and the reassurances of health care professionals:

7.24 Well, all your *brave* feelings that, you know, it’s going to be all right and you’re going to live — when it actually happens and you’ve got to face the fact that it’s gone, and that you’re not complete anymore, and you’re not a woman any— well they keep telling me I am a woman, but I don’t think that I am. Now that hurts. [Tears begin to flow] [Emphasis added] (Doris, l 210-219)

Doris demonstrate the continuation of her emotional pain by the joint presence of a verbal symbol (“Now that hurts”) and a non-verbal symbol (tears). When the interviewer quietly

acknowledges these symbols, by simply stating “And it still hurts?” Doris agrees and again provides a form of rational justification for her emotions:

7.25 Yes. It'll hurt 'til the day I die. I mean — what I've lost is comparable to a man losing his penis. This has — so a man would feel exactly the same way I feel. I've lost my womanhood, and he'd lose his maleness, and that's just what it is. There are other things that identify me as a woman but deep inside I don't feel that anymore They [other people who try to convince her that she is still a woman] haven't lost it, *so they really don't understand*. And as yet there isn't a group of people [more tears] that I've got — that've got the same as me that can get together and talk about it. I wish there was. It would make it much easier. ... [named nurse] at the ... [named hospital] was great. She took me through it — *but I still didn't talk about things because I wasn't ready to*. Now, perhaps two years later, I'd like to know how other people felt. [Emphasis added] (Doris, 1 223-258)

In response to Doris' current emotional reaction the interviewer inquires as to what is happening for Doris at the present moment. In her reply Doris embeds a symbolic comment about 'hearing' her and then volunteers more information about her private reality concerning her experience of fear as an integral part of her illness experience:

7.26 Doris: I haven't talked about it before have I? It's kept inside. That's all right. *I just hope you can hear clearly*. — But that's what happened. And I was frightened like everybody else.

Interviewer: What were you frightened of?

Doris: Dying. I didn't want to die. [Emphasis added] (Doris, 1 276-281)

These extracts also demonstrate the difficulty Doris experiences in developing a new self-image. At a cognitive level Doris knew that part of her body would be forever changed by the surgery. However, the emotional impact of surgery does not occur for Doris until some time after the event when she begins to interact with the realisation that her perception of 'womanhood' is predicated on the existence of intact genitalia.

Although Doris obviously uses humour as a coping mechanism, it is important to note that, throughout her illness narrative, humour is frequently juxtaposed with disclosure of emotionally painful experiences. The effect is like presenting the listener with a choice: either respond to the humour or “hear clearly” and explore further Doris' subjective reality. The listener is invited to choose whether to take up the seductive option to talk about the humorous ways she copes with her illness experiences or to “hear clearly” that there is more to her experience than just humour; to choose between the public reality of the

common sense and medical discourses or to share her private, subjective reality. For example, in discussing the support given by her ex-husband and family Doris again juxtaposes humour and emotional pain:

7.27 Doris: They've dragged me back laughing and joking and that — ahhh — he keeps saying about me “Oh she's been spayed but she's still OK” [laughs]. So with people like that — uhm -- giving you care and love and pulling you back by your boot straps you do get better. *But it still hurts sometimes*. There are still times when I get upset [voice breaks]

Interviewer: When are those times?

Doris: ... It might just be, I'll see a couple — uhm — who are very close — and I'll — [voice breaks] — that [intimate] part of my life can never be anymore — ahhh — I don't know, it's just I think comes when I see other people being close and I know I can never be that close to somebody again [begins to cry] [Emphasis added] (Doris, l 317-340)

Doris' form of humour and the manner in which it is presented is infectious. It is difficult for listeners not to be seduced into continuing to explore Doris' experiences within the elements of the common sense and medical discourses. However, Doris also introduces verbal symbols indicating the existence of a very different subjective reality.

Doris even acknowledges, later in the interview, that her laughter and joking at her initial diagnostic consultation masked other strong emotions. When she first consulted her general practitioner she laughed and joked during the consultation:

7.28 Doris: And while he [GP] was investigating [laughs] I said to him, “... [daughter's name]”, he said, “What's she said now?” I said, “She reckons I've got vaginal warts”, and we laughed like mad and we were having hysterics and I said, “It isn't, it's cancer isn't it?” and he said, “Yes.”

Interviewer: So what were you feeling as well as the laughter, when you talked about cancer?

Doris: Fear [softly spoken]. That's quite natural. (Doris, l 129–416)

These verbal symbols can also be explicit. For example, after providing an initial overview of her experience of diagnosis in terms of quiet acceptance and without undue emotion, Doris concluded by indicating that there was more emotion to her story but that she was not prepared to discuss it at that particular point:

7.29 That was the first bit. *Later on the panic hit*, but we can talk about that later [impish tone]. [Emphasis added](Doris, l 183-185)

The implicit message in this comment is that Doris feels comfortable enough to indicate that there is more to her story, and she may be willing to discuss it, but she still needs further evidence from the interviewer that any expression of strong emotions she may display will be accepted. Doris returns to the issue of fear at a later point in her narrative after the interviewer had responded to her imbedded verbal symbols (see extracts 7.21 page 190, 7.23 page 191, 7.24 page 191, 7.26 page 192, and 7.27 page 193). In reflecting on the initial diagnosis and surgery Doris refers to her initial reaction as one of shock and indicates that some time later she experienced fear. In discussing this second experience Doris does not use humour but spontaneously and openly acknowledges her panic:

7.30 I found a lump here [points to side] and they weren't sure what it was. My whole side blew up. That frightened me for a whole week until we got the results back and that fear was more than it had been the first time. (Doris, 1731-738)

Nonverbal symbols

Non-verbal behaviour, such as crying, is simultaneously a form of communication and a form of text in which discourses can be found at work (Parker 1992). As with many forms of non-verbal communication, crying is ambiguous and open to misinterpretation by observers (Adler & Rodman 1991). As a form of text (a delimited tissue of meaning reproduced in any form that can be given an interpretive gloss - (Parker 1992)), crying is associated with a number of discourses (e.g., pain, joy, relief, parental pride, exhaustion, grief or fear). Unless the listener makes an effort to identify the actual meaning crying has for the individual, incongruencies or misinterpretations can occur. Such misinterpretation is prevalent in situations where a particular discourse dominates in providing the rationale for specific behaviour. For example, the discourse of anticipatory grief defines how individuals are expected to react: a person who has a life-threatening form of cancer and is crying must be experiencing grief in anticipation of future losses (e.g., Aldrich 1974; Knott & Wild 1986; Middleton et al. 1991). However, the individual may be crying for any one of a number of reasons other than grief or sadness (e.g., experiencing pain, receiving good news, being over tired, feeling frustrated or fearful) (Engel 1961). The effect of outsiders imposing their belief system, or interpretations, on individuals is that conflict and tension is created for the individual who then begins to doubt their own experience and understanding of their own emotional response. As a consequence the individual may accept the imposed belief (Wortman & Silver 1989) or learn not to talk about their feelings with others. For

example, at one point during her narrative, Betty began to shed tears as she talked about how the overwhelming feeling of wanting to quit often arose for her. In response to a question to clarify what her tears were about, Betty identifies them as tears of fear, rather than of sadness. She also explains how others generally respond with clichés (elements of other discourses) to her shedding tears:

7.31 A lot of people [patients] will say the same thing, it's not sadness — it's — fear — that makes you cry — and [onlookers] say, "There, there dear. It's all right — things will get better." — and you think 'How would you know! [Stated emphatically and loudly] Leave me alone, *I'm scared* stupid over here people. It's not that [sadness or grief].' But then you say to them, "I know that" and you sort of go along with that's what it is. — you cop out. You think, 'Oh well, that's what it is. I must be just upset because of this —' but I'm not — and I said to ... [husband] on numerous occasions, I said, "I'm not sad because I'm going through a bad patch. I'm not feeling sorry for myself," I said, "I'm upset because I'm not handling it as good as I think I can." [Emphasis added] (Betty, 11431-1478)

In this extract Betty demonstrates two processes, namely reconceptualising the self and role taking. During interaction with aspects of her illness experience, Betty sheds tears. When an observer responds to her crying by offering the platitudinous responses "It's alright" and "things will get better", Betty immediately thinks to herself "How would you know!" However, instead of responding with this confronting comment, Betty engages in the process of role taking. She believes the observer is trying to be helpful (as she would be if the situation was reversed). As a result, she selects the more 'appropriate' response "I know that". This response symbolises Betty's understanding that the person is demonstrating care for her, even if the interaction is not personally helpful for Betty. Engaging the process of role taking does not stop with Betty's verbal response. She then believes that this person, as a member of the medical community, must have a better understanding of the illness experience. Consequently, she is 'persuaded' to accept the other's version of events and 'disregard' her own feelings and self understanding. She begins to perceive herself as wrong and her emotional response as inaccurate. However, when encouraged to give her interpretation of her reality, Betty acknowledges she is frightened about not living up to her previously developed self-image as someone who is tough enough to handle any situation.

This extract also demonstrates a form of socially enforced 'rationalisation'. That is, individuals' reality is not accepted by others (a form of social denial) and they are coerced

into changing their perception of reality to that of the others. This rationalisation occurs because the individual needs 'support' from other members of the community during this potentially isolating experience.

An example of crying as a form of non-verbal symbol indicating a different emotional response that also failed to be acknowledged by others is provided in extract **6.32** (page 161). As indicated in the discussion of this extract Josie expressed her sense of frustration, at her verbal messages being ignored by the oncologist, by crying. Not only did the oncologist dismiss Josie's verbal symbols but he also walked away from her when she began to cry. He did not take the opportunity to check with Josie what her tears signified. This same oncologist ignored another patient's verbal responses concerning the site of her pain. In this incident (extract **6.50** page 169) the patient expressed her sense of frustration at being ignored by "thumping" the doctor. It was only after this unusual form of response that the oncologist listened to Betty's opinions.

Facial expressions are another form of non-verbal symbol. These too can be misinterpreted and their subjective meaning requires clarification with the individual. An example of a facial expression being misread is provided in extract **5.53** page 136. In this extract Betty relates an incident in which the stomal therapist responds to Betty's facial expression. Betty comments that "She [stomal therapist] must take one look at your face and know you're having a bad day". As indicated in this comment Betty thinks that the stomal therapist has accurately 'read' her facial expression. However, although asking Betty if she is having a bad day, the stomal therapist immediately follows the question with the recommendation that Betty "just cry and get it over and done with". Although Betty explicitly states she doesn't want to cry because she thinks she will be making a "fool" of herself, the stomal therapist ignores this response and continues to impose her 'understanding' of the situation by encouraging Betty to cry. However, Betty is having a 'bad day' not a 'sad day'. The stomal therapist not only misinterprets Betty's facial expression but also denigrates Betty's self-image of being tough enough to handle anything (see extract **5.51** page 135).

It is apparent that the stomal therapist has a preconceived idea about how Betty should respond and is imposing her beliefs on Betty, albeit in a jovial, lighthearted manner. It is also apparent that the term 'bad day' means different things to both the stomal therapist and

Betty. It appears that, for the stoma therapist, 'bad' means 'sad'. However, as implied in her response to the interviewer's question in extract 5.53 (page 136), for Betty, 'bad' means something quite different: in this instance, having difficulty maintaining a stoical self-image, keeping things to herself and not being a 'wimp' (see extract 5.51 page 135).

An individual's need to discuss their private reality may be so great that when their verbal symbols are not appropriately acknowledged some other form of 'enticement' may be offered by the individual in an attempt to have their concerns addressed. For example, one informant, an ex-nurse, states that she had considerable difficulty trying to get answers to her questions and finding someone to talk to about her illness experience. She was open about her difficulty coping with her emotions but could not get people to respond to her and listen to her subjective experience of living with a life-threatening illness. She was so desperate to have people talk to her that she began to take a tin of "Minties" when she went for treatment or routine hospital visits. In offering health professionals a Mintie Martha was trying to entice them to pause for a while and listen to her intense experience of emotional pain and torment:

7.32 Martha: You go to a doctor and you say, "I need to talk to someone" and they say, "See a psychiatrist", or "You're having a panic attack, look I can't do anything about it". "But, I want to talk." ... Nobody understood. Doesn't matter who it was.

Interviewer: Nobody understood what?

Martha: The fear — the pain — the suffering ... it didn't matter what — drugs the doctors prescribed — what medicine they gave me — what injections I had for pain — you close the door at night and you scream your lungs out — the silence during the night and you — vomit everyday ... everyday you look at a meal, you can't eat it, you dry retch — you can't go near a hospital because you get a phobia about it in the end — — all because they [medical staff] never took time to explain to me what it is — and what's going on — and they tell you, "You're a level of six — your blood is level six, your blood level is eight, and your blood level is five, or four" ... the only thing I got, right through [my experience], is that I wanted miracle answers — about three months ago I went to the ... [named hospital] I said, "I'm having a break-down" — — they couldn't give a fuck — [begins to cry] — about me having a break-down ...

Interviewer: So you really wanted the nurses and doctors to listen and talk to you?

Martha: I'm not blaming the nurses at all. The nurses done [sic] their dirty work. They have to, or they get out — and I think the doctors should do their own dirty work — "Oh how are you?" they'd say.

Interviewer: What do you mean "dirty work"?

Martha: Sit and explain. Tell the patient what it is all about. Don't put a patient in ... [named hospital] and not know what the radiation is. You go in

there and they — it's just horrific — you don't know what was coming or going. So you take a tin of Minties and you would say, "Would you like a Mintie? Would you like a Mintie? Will you talk me through it? There's just this giant ugly thing is on top of me" ... [it was] torment, *because nobody understood*. [Emphasis added] (Martha, l 353-535)

Unfortunately for Martha, even this enticement was not effective in having health care professionals listen to the intensity of her emotional turmoil and fear. As implied in the emphasised phrase, this failure to have her subjective experience acknowledged and accepted increases Martha's sense of isolation, fear and neglect.

These oblique or symbolic references allude to the existence of a reality of living with a life-threatening form of cancer that is different to that identified within the dominant discourses (e.g., hope, common sense, medical). The listener who acknowledges and responds appropriately to these symbols indicates interest in hearing the individual's subjective experience of illness. Such listeners also indicate a preparedness to acknowledge the existence on an alternative discourse to the dominant discourses. As a consequence of receiving appropriate responses to these symbols informants begin to discuss their subjective experiences more openly and in terms that are often outside these dominant discourses.

Variation in definition of social objects

These verbal and nonverbal symbols, indicating the existence of a subjective reality that differs from the socially endorsed public image, are often missed, or misinterpreted, by health care professions. For example, Betty describes a situation where she was informed that there was nothing more that could be done for her at the moment (see extract **7.64** page 219) and she realises that perhaps she must go through this experience alone. She then indicates that there is support within the hospital but only from those who have been through the cancer experience:

7.33 But it's not the support of the nursing staff. It's the support of the stoma nurse there ... [name]. She's been through cancer and she knows what fear is like and what everything's like and she comes up to you and says, "Having a bad day are we?" *She must take one look at your face and know that you're having a bad day*. [Emphasis added] (Betty, l 973-979)

In the emphasised sentence Betty indicates that she is aware of the importance of nonverbal symbols. She also implies that not all health care professionals attend to these nonverbal symbols.

Patients also attend to the nonverbal symbols given by staff as well as other patients and often glean information about 'bad' news before anything is said. For example, prior to being told about the necessity for a major operation Josie states:

7.34 I knew before they told me because *I could see in their faces they felt bad about having to tell me. — I feel that they feel sorry that they have to tell — they don't like having to tell anybody [bad news] — they have — compassion for people.*
(Josie, 1 1912-1915)

In this extract Josie perceives the doctor's facial expression as a non-verbal symbol, despite the fact that it may, or may not, be intended as a symbol by the doctor. At the same time, Josie engages in role taking. She is influenced by the community expectation that members of the medical community are compassionate people who do not like upsetting patients in interpreting the doctor's facial expression as a symbol indicating that he was feeling sorry that he had to convey 'bad' news. Without data from the specific doctor concerned it is not possible to indicate whether or not his facial expression was intended as a symbol.

Even among patients these nonverbal symbols are not always accurately identified unless they are checked with the individual concerned. For example, Doris describes in her narrative an incident soon after surgery when she and other patients were receiving results of previously conducted pathology tests conducted (see extract **6.63** page 175). Doris observed one of the patients crying as the doctor spoke to her and made the interpretation that this person was receiving bad news. In response to her inquiries some time later Doris was informed by one of the medical staff that the other patient was crying with relief because she received good news about her pathology tests.

Other informants imply that their subjective experiences had not been heard, acknowledged or explored. For example, Doris recounts that after her vulvectomy she thought that she was no longer a 'woman' but health care professionals continued to provide reassurance that she was a woman. At the time of the interview Doris begins to shed tears as she speaks

of this incident almost two years previously. She indicates that she still does not feel a woman and says of the staff:

7.35 ... they haven't — they haven' lost it. So really they don't understand. And as yet there isn't a group of people [sheds more tears] ... that've got the same as me that can get together and talk about it. I wish there was. It would make it a lot easier ... Now, two years later, I'd like to know how other people felt. (Doris, l 243-258)

When asked what her tears being shed at the time of interview were about Doris states:

7.36 I haven't talked about it before, have I? (Doris, l 267)

Embedded within these comments is the implied suggestion that, previously, others had not picked up her symbols about her subjective reality. At the time of interview Doris indicates that she would like to talk with others who have gone through the same experience as herself.

Another informant suggests that only individuals who have lived through the experience of cancer know what it is like. In her comment, Martha implies that health care professionals do not really understand the experiences of patients living with a life-threatening form of cancer:

7.37 Martha: They should have people who has [sic] got the cancer, or had had it — ahhh — to work with these people [cancer patients].

Interviewer: Are you saying then that you think that only somebody that's had cancer can help somebody that's going through it?

Martha: Yeah, One hundred percent. (Martha, l 1770-1779)

These extracts raise an important issue, namely, the discrepancy between informants' and health care professionals' understanding of living with a life-threatening form of cancer. It is apparent that some social objects associated with cancer have different 'uses' for each group and, therefore, are defined differently. Although discussing the same object, each group has definitions of that social object that differ in varying degrees.

Experiential discourse of life-threatening cancer

As patients progress through the diagnosis and treatment processes they become aware of two important aspects of their subjective experiences that they perceive are not included as elements of the dominant common sense and medical discourses. Perceived beliefs and practices within these dominant discourses do not support the discussion of strong

emotional responses to the illness experience, nor do they facilitate patient discussion of thoughts about their future. Consequently, individuals living with a life-threatening form of cancer develop their own ways to categorise, describe and make meaning of their emotional responses to the ongoing illness experience and, in particular, thoughts about their future. That is, individuals develop a 'experiential' discourse of life-threatening cancer that has elements common to both dominant discourses and some elements that differ from those within both the common sense and medical discourses.

Grief

Beliefs within the professional discourse of anticipatory grief suggest that individuals facing their probable death will grieve in anticipation for future losses. However, in marked contrast to these beliefs, only two of the nine cancer informants in the current study specifically raise the issue of grief relating to their illness experience. Toward the end of her narrative Betty discloses that she is experiencing grief. When asked to identify the cause of her grief Betty indicates that it is for body parts that are missing as a result of surgery:

7.38 That's another thing, grief for what's missing — for what's not going to be there ever again. It's like having; — someone said it the other day when I was in hospital, it's like having a limb amputated. I've had things amputated and that aren't there anymore, and — sometimes, believe it or not, I still get the urge to go to the loo, and there's nothing there ... It's like the nerve endings haven't quite got through to the brain that there's nothing there any more. And I thought, 'Oooo, that's a scary feeling', you know, having this thing that you're supposed to go to the loo and you wake up in the middle of the night and it's not there. It takes me a while to get my bearings ... having a hysterectomy ... it's a grieving process. (Betty, 1947-1996)

The second informant to raise the issue of grief does so in the context of her illness-related loss of independence. Jan has prized her independence highly but since the cancer spread throughout the bones in her left leg she is forced to use crutches. This resulted in severe restrictions to her mobility and capacity to undertake previously routine daily tasks. She is currently dependent on her husband for some aspects of personal care. Jan also recounts how she is still grieving for changes that occurred in her relationship with her husband twelve months prior to her own diagnosis of cancer. Her husband's previously undisclosed homosexual lifestyle had been exposed publicly, he lost his job and his seroconversion

discovered. These events resulted in considerable changes in the couple's intimate relationship for which Jan is also grieving.

A third informant did not mention grief specifically but indicates that she "broke down and cried a number of times". There were two reasons for these periods of 'grief'. Firstly, when she acknowledged that, as a result of the effects of the vulvectomy, she had lost her 'femininity' (see extract 7.25 page 192). Doris also became 'upset' when she saw "other couples being close" and she was reminded that she had "lost" that form of closeness for herself (see extract 7.27 page 193). Secondly, Doris became upset when she realised that her illness experience had so changed her life that she was no longer able to engage in, or enjoy, some of her former activities such as acting.

Beliefs about the future

The strength of the belief within the common sense discourse that links cancer with inevitable death means that the initial reaction of individuals, to their suspicions that they might have cancer, or the actual diagnosis, is to believe that their early, painful death is inevitable. This belief is in conflict with the belief within the medical discourse that early detection of cancer provides a better chance of cure and possibly less radical treatment (Lowenthal, 1996). As a consequence of these conflicting views individuals are confronted with a dilemma: whether to believe the element of the common sense discourse that equates a cancer diagnosis with inevitable death or whether to believe the perceived contradictory element of the medical discourse and the medical staff's reassurances that cancer is not a death sentence. Since there is no decisive evidence supporting either case individuals come to believe that their immediate and long-term future contains considerable doubt and uncertainty.

Despite the medical profession's reassuring use of the military metaphor (see Chapter Five) patients receiving treatment for life-threatening cancer perceive that their future contains little certainty. There is a considerable amount that is unknown about the illness experience: how individuals will respond to specific treatment; whether treatment will result in total cure; whether the cancer will spread; whether they will experience treatment side-effects; whether they will be able to cope with the treatment; whether they will experience severe pain; whether they will die as a result of the cancer.

Beliefs within the common sense and medical discourses and the discourse of hope, encourage individuals to take 'one day at a time', to think positively at all times and not worry about the future. However, there are times when individuals living with a life-threatening form of cancer become disheartened, anxious, feel frustrated with their experiences and contemplate quitting their 'fight' with the disease. Individuals are confronted with another dilemma: what do they do when their personal experience may conflict with either, or both, the common sense or medical discourse. In addition, thoughts of the future are seldom far from the individual's mind as they are triggered by both illness-related and non-illness-related incidents. Eight of the nine informants in the cancer sample indicate that fear is their most frequent response when thinking or talking about their future.

Discourse of fear

Fear is the dominant discourse associated with individuals' subjective experience of living with a life-threatening form of cancer. The feeling of fear is described in a number of ways. One informant, after being told by the oncologist that he could not give her a prognosis or even "hazard a guess" as to her future or a possible percentage chance of survival, vividly describes her meaning of fear:

7.39 If someone had pulled a gun on me and said, "I'm going to shoot you", I wouldn't have been more scared ... It's a terrible feeling — uhm — like I said, it's like someone's pulled a gun at you and they're poking it right at your face and they're crazy — and you know they're crazy and it's so unpredictable you don't know whether they're going to pull the trigger or whether they're not — and it's just that type of fear — it just sort of gets a hold of you and your whole body cold sweats — uhm — you just feel as though someone has grabbed a hold of your gizzards and they're reefing them around like, you know, it's awful. (Betty, 1614; 908-920)

This particular metaphor is full of symbolism used by Betty in illustrating to the listener the fear-filled meaning of her illness experience. Also embedded within this statement about fear are references to the related discourses of dying, death, the unknown, being out of control, and the body. For Betty, there are a number of symbolic links between the metaphor and her experience of cancer; the gun symbolises the cancer and it's potentially life-threatening nature; "someone had pulled a gun on me" symbolises a belief in the external nature of the disease and being out of control; "I'm going to shoot you" also symbolises the cancer and illustrates Betty's belief that the disease is definitely life-

threatening; “they’re poking it right at your face” symbolises the serious nature and proximity of this life-threatening disease; “you know they’re crazy and it’s so unpredictable” symbolises the irrational and unknown qualities of her experience and future; “it just sort of gets a hold of you” also symbolises her feeling of being out of control and helpless; “cold sweats” symbolises extreme fear; “your whole body” symbolises the all-encompassing, physical nature of the reaction Betty experiences to such extreme fear. To add to the graphic nature of Betty’s description of her meaning of the illness experience she also uses another metaphor to illustrate her physical reaction. Her bodily reaction of “cold sweats” is not isolated. Having “someone” “grabbing” hold of your “gizzards” also symbolises Betty’s belief in the external nature of the origins of this fear and its sudden, unexpected appearance and “reefing them around” symbolises the extreme nature of this fear and lack of control. This second metaphor also symbolises Betty’s sense of helplessness at having things done to her and without her consent.

Betty indicates that fear is an emotion that is continuous throughout her illness experience:

7.40 It’s always there. That fear is always standing right behind ya [sic] and death. Both of them. To me they’re the same thing — fear and death — and they’re standing right behind you and they’re tapping you on the shoulder saying, “Ha, ha.” (Betty, l 2038-2050)

This extract is also full of symbolism. Betty, by personifying both fear and death and merging them into the same ‘being’, externalises the cause of her emotional response. This could be seen as her reaction to the discourses on hope and personal culpability that require the individual to respond positively to their illness experiences and take responsibility for their situation. Betty is indicating symbolically that it is difficult for her to maintain a positive attitude if she admits that her fear response is internal. In personifying her fear she is, in one sense, distancing herself from the creation of her personal emotional reaction. Fear is not only perceived as external to Betty but also as ‘stalking’ her and, therefore, is responsible for ‘causing’ her reaction. Furthermore, “standing right behind you” and “tapping you on the shoulder” symbolise the external nature of the cause of her fear, and at the same time, the proximity and intensity of the fear. Betty is unable to ‘escape’ this fear as not only is it intruding into her attempts to ‘think positively’ by physically ‘touching’ her but also, she “hears” it “laughing” at her. Consequently, she is reacting to an external

'cause' and, therefore, in responding with fear, is not personally culpable for her emotional reaction.

Another informant described her experience of fear:

7.41 I'll never forget the feeling of fear ... it was just a wave of fear. It was like I knew now that this was it. I was going to find out what was going on; what was going on in my body. But, it was this fear that now I've got to face it. I can't deny it any more; something is there in my body; something is going on and now I'm going to find out what it was. But, it was just this absolute wave of fear. (Jan, l 510-520)

In this extract "wave" symbolises the overpowering and overwhelming external nature of the experience of fear. Jan is also, in a sense, 'externalising' the cause of her fear. She is not responsible for 'producing' this "wave of fear" that engulfs her. As in the previous example this can be seen as a reaction to the discourses on hope and personal culpability. Both these individuals are indicating that an 'external' stimulus is responsible for creating their emotional response. Therefore, as they are responding to an external stimulus they can not be held culpable for responding in ways contrary to beliefs within the discourses of hope and personal culpability.

Symbolism is used by another informant to identify her fear. Her deteriorating physical appearance is symbolic of what she perceives as her rapidly approaching death:

7.42 Nobody understood the torment and pain that 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 of is coffins — and you get — already in the coffin ... [saw death every day — and coffins every day — no matter what I tried to do -- [to] block it out. (Martha, l 539-548).

Martha's perception is that other people did not understand her predicament. This informant also personifies death and identifies it as her 'tormentor'. Rather than perceiving death as a biological event occurring within her body she externalises it and sees 'death' staring back at her from the mirror each day. For this informant seeing a "skeleton" in the mirror and thinking about "coffins" and seeing herself "already in the coffin" is a symbolic representation of her belief that her experience of cancer will ultimately end with her death. Again, the words "torment and pain" are symbolic of the individual's belief in the external origins of the cause of her reaction. That is, the informant is responding to something being

'inflicted' on her by an external 'tormentor' - death. Consequently, she is not 'responsible' for her subjective reaction. Furthermore, in this extract, "torment and pain" are used as more socially acceptable synonyms for 'fear'.

Patients' fears

All informants in the cancer group reported that they experienced fear at some time during their illness experience. Fear is always discussed in terms of the future. It is often first discussed in response to the presence of unusual symptoms that raise the possibility of cancer being present. Fear is then experienced in association with various incidents that occurred throughout the diagnostic and treatment processes and that triggered thoughts about the future. Within the medical discourses on dying and death these fears are discussed as variations of general death anxiety or fear of death (e.g., Raphael 1985). However, this approach does not accurately reflect the complexity of the individual's experience of fear and its meaning. It also does not differentiate between the concepts of 'fear' and 'anxiety'. For example, individuals experience feelings of apprehension and discomfort when they think that they will encounter pain at some time in the future. It is these thoughts about pain and its ramifications that 'cause' the apprehension and discomfort. Thus the individual is said to be experiencing fear of pain. Anxiety is used to describe feelings of apprehension and discomfort that result from no known identifiable cause (Freud 1959; Kalish 1985). For example, although individuals speak of "fear of the unknown" they are actually talking about anxiety as the cause of their feelings of apprehension and discomfort are not readily identifiable. In this situation individuals are experiencing anxiety because they are unable to identify precisely the cause of their feelings of apprehension and discomfort.

Classification of disclosure

Beliefs within the discourse of hope impose limits on the way in which individuals can discuss experiences that are perceived to be 'negative'. These beliefs have the effects of discouraging the acknowledgement or expression of emotional responses such as fear and anxiety. In contrast to this socially sanctioned value against the expression of these emotions, the discourse of fear dominates individuals' responses to living with a life-threatening illness, therein creating a dilemma for individuals living with cancer. However, as has been demonstrated above, individuals attempt to resolve this dilemma by talking

about it with another person. The need to discuss their subjective response to the illness experience is demonstrated by the provision of appropriate symbols.

Disclosure of fear and its meaning for the individual is not a one-off event. It occurs at any one of three levels and is dependent on the emotional intensity of the material for disclosure, the individual's comfort with such disclosure and their assessment of whether their responses will be accepted and not devalued. This comfort with disclosure is dependent on whether the individual believes that their symbols have been appropriately acknowledged and whether the current environment is one in which their issues and emotional responses are likely to be accepted rather than devalued. For example, one informant, Betty, spoke about how others generally interpreted her display of tears as her response to sadness (see extract 7.31 page 195). As a result of not being understood or accepted Betty explained how she acquiesced to the interpretation of others rather than disclose what was really happening to her. However, she then recounts how she explained to her husband that, in contrast to beliefs within the discourse of grief, her tears were in response to her fear of not being brave enough to handle her illness experience.

First level disclosure

First level disclosure is voluntary and involves a description, in general terms, of the individual's experience. That is, the individual initiates primary description of their fear and, in providing the information in general, socially acceptable terms, does not identify the specific cause of the fear. The strength of the socially sanctioned value against expressing emotions is apparent in that individuals also frequently provide some form of justification codicil for their fear response. That is, they provide some form of socially acceptable explanation for their response.

All informants in the current study described their reaction of fear to either their suspicions that they may have cancer or their actual diagnosis. However, first level disclosure is not always expressed in the same manner. Some informants openly describe their reaction of fear: others either imply they feel fear or refer to it symbolically. For example, one informant detected an unusual lump, which she thought might indicate that she had cancer and describes her reaction:

7.43 I'd had a lump under my armpit and I rang the doctor *in a panic* and said, "I've got a lump under my armpit, *for God's sake what is it?*" [Emphasis added] (Doris, 1 81-84)

The emphasised phrases in this extract identify this informant's socially acceptable experience of fear. However, she does not specify the precise nature of her fear. This is not an isolated incident for this informant. Doris indicates that since the original diagnosis there were three times when changes in her health status led her to suspect that the cancer had spread. She indicates that each time she was frightened and again provides a justification codicil for her response but does not identify the specific cause of her fear:

7.44 Doris: So three times since I had it [diagnosis] nearly two years ago we've had a scare. It's getting less and less.

Interviewer: What's getting less and less?

Doris: The fear. Every time there's another lump or something else ... because you're never really sure [if it's cancer or not]. (Doris, 1 44-56)

Other examples of first level disclosure with this informant are:

7.45 Then when he told me after the operation that it had got my lymph nodes I can remember *panicking*. [Emphasis added] (Doris, 1 1311-1313)

7.46 I found a lump here [pointing to side] ... that frightened me for a whole week until we got the results back ... it could have been the cancer extending further. (Doris, 1731-765)

7.47 I think the thing that also frightens me, because my grandmother had the same thing, as far as my mother knows. She kept going in and having growths cut off and she died of cancer I got the cancer in the same place as she did. Which they said was interesting. So that's gone into the history records. Now they can't say it's not hereditary any more can they! But she died of it. (Doris, 1 796-814)

Second level disclosure

Second level disclosure occurs when the individual identifies the cause of their fear. This level of disclosure often involves more emotion as individuals begin to focus more specifically on identifying their fears (e.g., fear of dying, fear of death, fear of pain, fear of treatment) and anxieties (e.g., anxiety about separation, anxiety about unknown future). This level of disclosure may be provided spontaneously by the individual or in response to the listener's clarifying questions. For example, after initially describing the circumstances around her diagnosis, and indicating in general terms that she was scared (see extracts **7.43** page 208 and **7.44** page 208), Doris indicates that she is "frightened" and again provides

the justification codicil that she responds “like everybody else”. When this first level disclosure is acknowledged with a direct question from the interviewer Doris responds with more specific information about her fears:

7.48 Doris: But that’s what happened. And I was frightened like everybody else.

Interviewer: What were you frightened of?

Doris: Dying. I didn’t want to die. (Doris, l 274-281)

Another informant makes a first level disclosure then, following the interviewer’s clarifying question, makes a second level disclosure about her anxiety about not knowing what was happening. Jan had been misdiagnosed with, and treated for, Paget’s disease some months prior to detecting a lump in her thigh. She was admitted to hospital for further diagnostic investigation and then referred to an orthopaedic surgeon. Jan describes her emotional reaction as she awaited the test results:

7.49 Jan: I had this whole series of tests, and I had to wait over the weekend and — he [doctor] came back on the Monday to me and he said, “There is a growth,” he said, “whether it’s malignant or not I can’t tell,” ... I might say that *I was packing it* during this time [said with great deal of emotion]. Controlling it very well on top, but it was like the not knowing

Interviewer: You mean fear?

Jan: Yeah, the fear of not knowing .. I could feel the fear ... [Emphasis added] (Jan, l 443-470)

Jan also acknowledges that during her previous diagnosis and treatment she had experienced fear that she may have cancer but, due to the strength of the belief, within the discourse of hope, in the need for responding positively, she did not openly acknowledge its existence:

7.50 ... [previously] the fear was there but I kept pushing it away and saying no ... you know, having to be so positive that you are blocking out any of the other side of it. (Jan, l 471-475) (see also extract **7.4** page 182)

The fear returned when the orthopaedic surgeon contacted Jan to discuss details concerning future surgery:

7.51 He rang me two days later. I’ll never forget the feeling of fear ... it was just a wave of fear. It was like I knew now that this was it. I was going to find out what was going on; what was going on in my body. But, it was this fear that now I’ve got to face it. I can’t deny it any more; something is there in my body; something is going on and now I’m going to find out what it was. But, it was just this absolute wave of fear. (Jan, l 509-520)

One informant, Martha, indicates that she has a number of fears; that treatment might kill her; that the cancer will return; that she will die suddenly while no-one is with her. During her treatment Martha has required a number of blood transfusion. With each transfusion she is frightened that the blood may be contaminated and she might become infected by HIV. She is also frightened that the transfusion may not help her. She states that she is fearful that:

7.52 ... I'll never go out. Whenever I go into hospital [I'm frightened] that I'd never come back out again. (Martha, l 335-336)

She also states she has fear about:

7.53 Having a blood transfusion. Fear! Is it going to be contaminated? Is it going to give me AIDS? Is this going to help me? (Martha, l 1489-1492)

Martha also states that she is frightened firstly that her children might come home and find her dead. She then discloses that she is frightened of dying alone and that no-one really cares or listens to her subjective experience:

7.54 Martha: It's very frightening thinking that one day your kids are going to come open the door and they're going to find you bloody dead! — That you're going to be alone somewhere and you can't do anything.

Interviewer: So that's terrifying?

Martha: Of course it is!

Interviewer: I can appreciate that — but it sounds like nobody else listens to that?

Martha: They don't care! You are a number! They don't give a shit! They don't give a fuck who you are! (Martha, l 1045-1058)

The social sanctions against expressing 'negative' emotions prescribed by beliefs within the discourse of hope are so strong that one informant is not able to acknowledge her own fear of treatment. Instead she projected her fears onto her children and says she is fearful for her children because they would have to go through a similar process to the one she went through with her father and his cancer treatment:

7.55 Scared for them! [children] I don't know — I want to see them grow up — I thought I'd be around then, you know? — 'cause I — you know, had dad sick for nine years, when I was a teenager, so — same for me — 'cause he wasn't really a dad for nine years. They [children] want to sort of live a normal life. Ending up having this all the time. I don't want to be in and out of hospitals — like dad was — and that was all we used to do was go and visit him — we couldn't go away at weekends because of dad or — you know, every second night go up and see dad — things like that for nine years — and I don't want my kids to go through that. (Susan, l 547-572)

In this extract Sue also implies that she is frightened that she will die and not be around to see her children grow up.

Individuals may also make second level disclosure symbolically. For example, one informant, Betty, did not refer to her private, emotional response to the lengthy diagnostic process until toward the end of her narrative when the interviewer asked whether there was anything else that Betty thought was important for an understanding of her experience (see extract 7.3 page 181). Betty began by saying that she had a lot of “anger” directed at herself for not seeking a second opinion when she knew that something was very wrong with her health. However, similar to Sue’s anger (see extract 7.6 page 184), Betty appears to be talking at a public level. The way in which Betty talks about the anger raises a question as to the legitimacy of the label: is it an accurate descriptor of her feelings or is it used because of the influence of the discourse of hope? Betty struggles to accurately identify the source of her “anger” before revealing that it was not anger but her fear, which stopped her from seeking a second opinion. Even in recounting this incident, Betty has difficulty acknowledging her fear and claiming it as her own. Instead she relates an incident in which another patient accurately identifies the emotion Betty is experiencing. However, when the interviewer seeks clarification of the accuracy of the second patient’s assessment, Betty responds with more disclosure concerning her fear. She was frightened of “that second opinion proving that I did have it [cancer]”.

Accepting second level disclosures at face value and providing interventions such as reassurance does not effectively address the patient’s issues. For example, providing reassurance that effective analgesics are available and will be provided to the person who expresses fear of pain is not dealing with the most important issue for the patient: the meaning pain has for the individual. Before developing any form of intervention it is necessary to understand the meaning severe pain has for the individual. That is, how has this particular person symbolically designated pain in all its forms and variations (e.g., physical, emotional, spiritual, social, excruciating, severe, strong, and mild).

Second level disclosure raises the question of individuals’ meaning. What does the individual mean when they use various terms such as ‘dying’, ‘death’ or ‘pain’? As is the

practice within both the common sense and medical discourses, the terms dying and death are frequently used by individuals living with a life-threatening illness as synonyms to refer to a process, an event, or a state. However, it is not always immediately clear what each term refers to. For example, in using the term dying, is the individual referring to the process of declining in functioning from health to death (often referred to as the dying trajectory (Adler & Rodman 1991; G aser & Strauss 1965)). Alternatively, is the individual referring to the actual event where life ends? That is, the event where the heart stops beating and breathing ceases with the outcome being that the individual is considered medically dead and no attempts at medical resuscitation are considered viable or undertaken. Similarly, 'death' is used to refer to both the event (cessation of life) and the state of being dead.

Third level disclosure

Third level disclosure occurs when the individual identifies various aspects of the meaning of their experience. This level of disclosure rarely occurs spontaneously. It requires an environment in which the individual believes that their explanations will be accepted and valued. Furthermore, it requires an effort from the listener to not only refrain from imposing socially acceptable ideas and values on the individual, but also active exploration of the individual's comments and checking conclusions with the speaker.

The narrative of one informant provides a very clear example of the necessity for clarification of terminology and meaning. Betty initially indicates that she is not afraid of dying. However, just over half way through the interview she acknowledges being afraid of "dying in pain" but it is not clear from this statement whether she is afraid of the process of dying or the event of death. It is necessary to clarify this statement to reveal Betty's meaning. It becomes clear that, for Betty, "dying in pain" means having "uncontrollable" pain. In turn, uncontrollable pain is perceived as the precursor of the event of death. Furthermore, for Betty the severity of the pain, in all probability, will force her to give up the fight against the cancer. It is then that Betty reveals that she is frightened of "not being brave enough" to continue the fight. Rather than fearing the dying process or the event of death, Betty is actually frightened of not living up to her own standards of being tough enough and the standard of behaviour 'prescribed' by the beliefs within the dominant

discourses, particularly the discourse of hope. She is fearful that she will experience so much pain that she will be 'forced' to quit and that if she does so, she will have failed the image she has of herself (see discussion of extract 5.51 page 135), her family, the community and medical carers' expectations of her as a person living with a life-threatening form of cancer. The following detailed narrative extract demonstrates the cause of Betty's fear and its relationship to the process of dying, the event of death and the discourse of hope.

7.56 Interviewer: A while ago you were talking about fear, and I wonder if we can go back to that ... what is it that you are actually fearful of?

Betty: Dying in pain! Now — that's the truth. I mean, I've been through pain — like last Sunday, that was painful. *I don't want to die in pain ... you can fight it as hard as you can. Like, I've known people even in there [hospital] that fight it — but the pain factor is something that you just wouldn't wish on your worst enemy ... it's not fear of dying — although I don't want to do it ... I don't want to die but — that's not what I'm afraid of. I'm afraid of going through all the agony.*

Interviewer: Right. Do you mind — I mean, — I notice that you're tearful. Is that about the fear or — I mean, what is that about?

Betty: It's — uhm — scary just thinking about it. Ahhh, I haven't had that much pain — considering the operation that I had — because they dose you up on morphine or pethidine or what-have-you, on drips, right? And you don't feel it — so — uhm — but I've — while I was in there [hospital] — just being a patient — *you can hear how painful it is — uhm — for some patients there. 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 — they were giving her morphine every three or four hours — and — you could literally tell the day she gave up trying to fight it. Um — it was 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. Um — I don't want to quit* [quietly sheds a few tears].

Interviewer: Right. So what are the tears about now?

Betty: [voice shaky] Just thinking that I could quit.

Interviewer: — you could quit — and it would be easy to quit?

Betty: Oh yeah [very quiet and full of emotion] — some days — when you're feeling really disgusting and you can't do anything — you've just got to sit here on the couch and watch the world go by — some days [begins crying again] —

Interviewer: I hate to be really clinical but I'm trying to understand what the tears are about, because I think lots of people misunderstand when people cry — and I'm not sure what it is for you?

Betty: [deep sigh] *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 trounce 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 and — ahh — some days I wasn't 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 you dare sit there and wimp out." ... It's a fear of not being what I expect to be. You know, not being tough, not being brave enough to face it — better than being a coward.

Interviewer: So it's got nothing to do with sadness?

Betty: Nope! [stated emphatically] It's a fear that I'm not going to be able to — uhm — face the next bit. A lot of people will say the same thing. It's not sadness — it's — fear — that makes you cry. (Betty, l 1284-1443)

In the above extract, Betty refers to a recent incident when she experienced severe pain as a result of eating something that she was unable to digest. Her comment "I don't want to die in pain" (line 4) does not clarify the 'process/event' issue. However, when Betty starts to talk about the "pain factor" the reader may begin to suspect that she is referring to the event of death rather than the process of dying. Betty's comment "I'm afraid of going through all the agony" (line 9) still fails to clarify whether she is afraid of the pain associated with the process or the event. During this discussion Betty begins to cry. When asked to identify what her tears were about Betty speaks about a recent stay in hospital where she observed a fellow patient with cancer who was in a lot of pain and receiving morphine "every three or four hours". Betty concludes that this patient gave up the fight because she was in so much pain (lines 16-23). It is evident from this story that Betty sees the experience of severe cancer-related pain as a portent of imminent death. She believes that such severe pain is difficult to fight, since it is not even controlled by morphine, and concludes that it is the pain that causes patients to "give up the fight for survival". After relating this story Betty makes the statement "I don't want to quit" (line 23). With her fears acknowledged, Betty discloses her feelings of being disheartened and frustrated by her experience of illness: she feels so "disgusting" that she is unable to do anything and can only sit and "watch the world go by". When asked to clarify what her current tears are about Betty describes her childhood growing up with two brothers and not daring to be a "wimp" (lines 35-39). This anecdote is analogous to the discourse on hope, and the related military metaphor. The belief that maintaining a positive attitude at all times and continuing to fight the enemy (cancer) is so strong that Betty is unable to refer to it directly. However, Betty acknowledges that her experience does not parallel that discourse and, therefore, she feels "disgusted" with herself. She then acknowledges that her fear is about "not being brave enough" to continue the "fight", rather than the dying process or the event of death. Betty is fearful of not living up to the values and beliefs within the discourse of hope and her own

self-image. This extract also demonstrates that although it is difficult to acknowledge fear of pain, it is more acceptable to do so than to admit having thoughts of personal inability to live up to the expectations prescribed within the discourse of hope.

The meaning of pain

Pain has different meanings for different individuals. As demonstrated in the above extract, for Betty, severe pain is perceived as the precursor of the event of death. For other informants severe pain in itself is not intolerable, but rather what it represents: dying without dignity. For example, at one point in her narrative another informant, Josie, indicates that pain generally does not worry her. She also indicates that she is not worried about the event of death as she has:

7.57 ... died twice on the operating table ... and to die it's just like being on a soft cloud, with soft curtain and something's pulling you that way and it's very peaceful and quiet and nice. (Josie, I 883-889)

However, Josie indicates that she has seen a “lot of people die” of cancer and she feels sad for them because “they’re so young” When asked what effect seeing so many people die has on her and whether it reminds her of what might happen to her, Josie briefly responds with thoughts about herself. She then quickly proceeds to discuss how women with cancer suffer a lot and die in a lot of pain. Josie raises the issue of dying with dignity and provides examples of her experiences with other women dying while she was in hospital. She also discusses, and gives reasons for, her involvement. It is through the symbolism of these other deaths Josie discloses that, for her, a dignified death means a painless death: experiencing pain during the event of death means that she will have no dignity in her death. Although she does not identify her fear specifically, it is evident from this extract that, for Josie, despite the availability of “pain relief”, a cancer death means having a painful experience that ends in an undignified death. It is also evident that she is frightened that she, too, will die without dignity:

7.58 Interviewer: You were talking about seeing other women die. What effect does that have on you? Does that ever remind you of what might happen to you?

Josie: Sometimes it does. Not a lot. I try not to think of dying — uhm — when I get sick — and when I have to go to hospital again and I've got to have another operation, then I tend to think about it a little bit — but — on the whole — no, I don't think about it.

Interviewer: Right. Even when you see other people who —

Josie: When I see them die — I just think that they've had hell on earth. They should go to heaven, you know. — they suffer a lot — women with cancer that — that die from cancer, have a lot of pain and a lot of suffering, and when — I

hate to see people suffer — and — I mean there's pain relief — but pain relief doesn't work twenty four hours a day — they're in pain a lot of the time and you lose your dignity — you do — I like to see them die with dignity.

Interviewer: So what do you mean by “dying with dignity”?

Josie: Uhm — to die nicely -- to go to sleep — *not to be in that terrible agonising pain before they die*. to have some comfort, to — I saw a lady die while I was in there [hospital] actually — her name was ... [name provided]. I watched her for days — in — just lying there — just like a vegetable — just waiting to die — but her heart was too strong. At about half past one on the Monday morning she went to sleep — I'd been out on the balcony having a smoke and ... I just felt that the woman had suffered just so much that — *how much can one person take was what I was thinking* — and she died at half past one and 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.

Interviewer: So the actual death?

Josie: The actual death itself. [Emphasis added] (Josie, I 1473-1540)

Josie then proceeds to describe her action after the patient's death. The nurses asked Josie whether she wanted to say good-bye to the patient as they had been treated at the hospital for the same length of time: four and a half years. For Josie the bare, single room in which the person died lacked dignity. She recalls that she wanted to have some colour “for the family” so made a posy of flowers and placed it at the nape of her friend's neck. It becomes evident in the following extract that, for Josie, it is important to have dignified and colourful surroundings after death. Furthermore, by providing a more dignified environment for her friend Josie hopes that someone will reciprocate her actions when she dies:

7.59 Josie: I went and said good-bye to her and it was very strange, standing there in the room with somebody that was dead. To look at her she was just like wax — just asleep — she looked so beautiful — I then went out and got — some carnations and roses and — gypsophila and put a — posy of flowers beside her because the room looked too bare — and it — brightened the room up for her family — I felt that — the family were coming to see her — just to have her lying there with nothing — would be just like being in a morgue — so I thought that something pretty would be nice for her so — I left that there for her.

Interviewer: So it was important for you to have nice surrounding for somebody?

Josie: Yes. Yes. *I would hope that somebody would do that for me when I died.*

Interviewer: I was about to ask that.

Josie: Yes, I would hope that somebody would do that for me because — those rooms — well, you're always in a single room — when you die — when you're very sick like that — they put you in a room by yourself — and it is just a room with a bed in it and it's — not very nice — it's a very cold atmosphere and I think if you can have something nice — you have nice things when you're alive so why not have them when you're dead? ... I think it's up to the relatives, but

a lot of relatives feel that they're [patient] dying — why bother with flowers — and why bother with nice things. But, I think it's important most important — even although you don't know, I think it's important still to have that colour and that brightness about you -- because it's not so sad for the people that are coming to see you — If you're just lying in a bed with nothing — then it — it's sad — it looks sad — and it's sad for the people that come to see you. If only they realised that — I mean, — I've seen it so — that's how I understand that — I would like things to be nice. [Emphasis added] (Josie, l 1553-1623)

Another informant, Jan, speaks freely throughout her narrative of her many experiences with severe pain caused by the cancer in her bones. She discusses her experience with pain control during her stay in an orthopaedic ward during her extended diagnostic process (see extracts **6.14** and **6.30** pages 152 and 160). Jan's fear of pain has two meanings. Firstly, she fears the actual experience of "agony" that is associated with severe pain and the length of time it will take to regain control of the pain. Secondly, she fears that her requests concerning treatment will be ignored. In essence, she is frightened that she may not be able to trust the medical staff to understand her subjective experience sufficiently to provide the most effective treatment in the future, particularly in relation to pain control.

Toward the end of her narrative Jan provides another subjective meaning of her fear of pain. When asked what she feared most Jan indicates that having pain at the time of her death means that her death would be without dignity:

7.60 I really fear — not dying with dignity. In other words, having pain. (Jan, 2207-2208)

Fear of pain resulting in an undignified death can also be expressed symbolically. For example, one informant clearly states she is not afraid of the event of death. To support her comment Doris compares the event of death to the closing of a door and an undignified death to having her foot caught in the door as she passes through. At the same time, by using the military metaphor Doris acknowledges how fearful she is of such a painful process:

7.61 I don't fear dying in itself, but the way of dying ...I don't think it's dying because that's like shutting a door. I guess it's just getting your foot caught in the door before you die It's the fear of seeing the pain they go through, you know, [I'm] frightened ... as I said I'm a coward with pain. So I don't want to go through the pain. That's what I don't want to go through. (Doris, l 894-921; 1901-1913)

Fear of pain is not restricted to the actual disease but also pain associated with treatment. One informant, who had been through a long process of treatment, experienced a period of remission before the cancer began to grow again, indicates that she too was fearful of the pain associated with treatment. She talks about the revulsion she felt when receiving her bone marrow transplant and her general fear of treatment. At the surface level this appears to be fear of the pain associated with having injections and the transplant process. However, she proceeds to disclose that her fear of treatment was really about her fear of being out of control and having things done to her:

7.62 Even though it was my own blood and marrow that they were transplanting back to me, when I saw it up in that bag, the bags in the thing coming down, it was like — [softly spoken] I don't want this in my body. This is something — like spitting into a glass and not being able to drink your own spit back — similar sort of thing. It was like [sucking in breath] I can't believe this *and all my fear of*, you know, needles and transplants and all this sort of stuff came back. It was like — *Oh God, this is all being done to me, I have no control.* [Emphasis added] (Jan, 1 1170- 181)

Third level disclosures are not restricted to fear. They can also include other issues that individuals may not have been able to discuss with either family members or health care professionals because of the perceived restrictive beliefs within the discourse of hope. For example, in describing her illness experiences, one informant discloses how she reacted to the chemotherapy she received. Jan indicates that she felt so out of control during the process of treatment that she gave up belief in herself. At the time, she also questioned her belief in thinking positively. As a result her positive imagery was replaced by one that was more actively negative. Her formerly positive visualisation of the cancer became one full of negative symbolism: black symbolising despair, and red mouthed intrusive creature symbolising the cancer actively gnawing at her tissue. Jan also acknowledges that it was important for her to acknowledge these experiences rather than pushing them away:

7.63 That was the most horrifying period I think I've ever been through. I felt in dissonance — like — I felt totally out of any control whatsoever. It was like I felt it was being done to me -- I was just so sick — it was the one time that ahhh — *it was like I gave up any belief in myself even, you know, — what's the use of being so bloody positive.* This thing is just — and I shifted my imaging — I haven't said this before, but when I used to use visualisation and meditation I had some pretty wonderful visualisations. It used to be a sea almond, a black sea almond, that uhm — gradually turned to green as the cancer healed. When it came back again like that, it became a little black octopus with a little red mouth, like a really intrusive creature It was just horrific. The chemo is pretty horrific, very intrusive ... I remember saying to

...[husband] at the time that I really wondered if I'd gone through with it if I'd known what the reality was going to be. But, I can see in hindsight, as I said to a lot of people since, pain passes. Things like this are temporary. You move on. *But at the time it's like you've got to experience it.* [Emphasis added] (Jan, 1 1123-1141)

What is socially acceptable, and encouraged by the perception of the expression of 'courage' or 'bravery', is the demonstration of concern for others. This projection of concern onto other family members can be so strong that the individual can lose touch with their own emotional response. For example, after her latest treatment Betty was informed by the oncologist that he could not even tell her whether she would survive. When asked, Betty was not able to identify, initially, how she felt because she was too preoccupied looking after the others involved in the situation. When pressed for her personal response Betty laughs as she begins to recount how she felt. She soon stops laughing as she talks about how she felt isolated and lonely and realised that she would have to face her future alone:

7.64 Interviewer: So how was that for you when he said that to you?

Betty: Well poor old — I mean — *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 — and — I had to ask the kids to go somewhere else — you know, it was like — it was all happening to somebody else — after a while — it wasn't happening to me — 'cause *I had to be brave* and sort of shoo the kids off and I got one of the nurses to take the kids down stairs and then — uhm — ...[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 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 — I need somebody to hold my hand” [stops laughing] Nobody came — not even the nursing staff — it was like they all knew — that really bad news had been told and they didn't want to get involved, 'cause they can't cope with it either.

Interviewer: How's that from your perspective, having everybody —

Betty: I felt isolated [laughs] I felt as though nobody loved me anymore and I was going to have to go through all this by myself — and I took a deep breath — and I said to myself “Well, I am. 'Cause they can't go through it for me and it's up to me and I'm the one that's going to have to put up with it all and do it all — and everything else” — and I thought “Well maybe it's right that — uhm — you do it by yourself” [Emphasis added] (Betty, 1 929-967)

Another informant also has difficulty openly acknowledging emotions that are contrary to beliefs within the discourse of hope, particularly that she is fearful of giving up the fight

against cancer. At the time of initial diagnosis, twenty eight years prior to interview, Josie had spoken about her fear of “being cut open and dying”. She spoke about numerous surgical treatments that she had undergone since the original diagnosis and was asked about the fear she experienced prior to the last operation. In her response she implies that she believes that severe pain can induce people to give up the fight against cancer. However, she quickly adds that, in accordance with the discourse of hope, she does not give up. However, when her implicit message is acknowledged Josie admits that, previously, she too felt that way. Josie then focuses her concerns on her husband before finally acknowledging her own fears:

7.65 Josie: For the last three operations I’ve gone in, I didn’t think I’d come out because I’ve just had so much anaesthetic and I had so many operations — *I’m getting tired of them*. And I think that the body can only take so much, and you can take so much pain that — *sometimes you want to give in* — but I don’t.

Interviewer: Are you saying that sometimes you want to give in?

Josie: Yes! [softly spoken]

Interviewer: But you don’t?

Josie: No [softly spoken and tears slowly begin to flow]

Interviewer: Right. What’s happening for you now?

Josie: Just thinking about it — — — just thinking about the operations — the actual thought — when they tell you that you’ve got cancer — they said to me — “You’ve got a malignant tumour” ... that was quite horrific It sort of shook ... [husband] a bit too. He broke down after he went away. I knew he was going to, so I said would he like to go home and he said, “Yes”. I felt for him more than I felt for myself.

Interviewer: Felt what?

Josie: I felt pain for him. I felt — really sorry for him because — I couldn’t — uhm — say to him “Don’t worry”, as much as I said “Don’t worry” he’d worry more — uhm — it hit him very hard — knowing what I was going to go through.

Interviewer: Was fear, associated with that feeling bad, for ... [husband] as well?

Josie: Fear — I was frightened — yes.

Interviewer: For — yourself and for ... [husband?]

Josie: And for ... [husband]

Interviewer: Both?

Josie: Yes! More so for ... [husband] *I was frightened — of what was going to happen to me because — I thought maybe I wouldn’t make it*. It was such a big operation and — I thought, “Well, hey you’re — not going to come through this one”, you know. I mean, I — I’ve been lucky. I’ve been very lucky I’ve been given a lot — I’ve — had a lot of chances. [Emphasis added] (Josie, 1 1019-1112)

Other influences of dominant discourses

The way individuals living with a life-threatening form of cancer express anxieties, fears and concerns about their future is influenced by certain behaviours and emotional responses being disenfranchised by the beliefs and practices within the discourse of hope, together with the beliefs and expectations within the discourse of anticipatory grief. That is, they are encouraged to remain positive at all times or grieve (within acceptable boundaries) for anticipated losses. However, they are implicitly discouraged from expressing anxiety or fear about what might occur to them after their death.

Anxiety about separation

The discourse of hope also influences the way in which individuals discuss their concerns about separation from family members. Unable to discuss their personal anxiety about separation from family members after death, individuals frequently discuss it in terms of either fear of leaving family members or fear for other family members. These fears are couched in more socially acceptable forms of expression: fear for others rather than for themselves. For example, one informant, who did not have a particularly close relationship with her children (they were in the custody of her first husband for fifteen years), provides an indicator that she is actually talking about herself. She first implies that she is frightened about leaving her family but then quickly adds the more socially acceptable response that she is more frightened for her husband and her family:

7.66 I used to break down and cry quite a lot. I was very frightened. Um — I was frightened, more so for ...[husband], leaving ...[husband] and my family. (Josie, 1 869-874)

Another informant expresses her anxiety about being separated from her family, after her death, in the more socially acceptable terms of concern for her daughters welfare. Again this informant identifies her anxiety in terms of the more socially acceptable emotion: fear rather than acknowledging her own anxiety. She was fearful that her daughters would not be able to cope without her as they could not even cook:

7.67 My biggest fear is leaving them — behind — leaving my daughters behind, because I know without me, they can not make it What they going to do? Who they going to turn to? Who is there? They got nobody. How they going to cope? Financially and otherwise? They can't even cook! That was the first — scary thing — that's leaving them [daughters] behind. (Martha, 1 340-341; 681-687; 1348-1349)

Anxiety about unknown future

Four of the nine informants in the cancer sample disclose that they were 'frightened' about the unknown. As with anxiety about separation, informants discuss this issue in terms of the more socially acceptable fear of the unknown rather than the more accurate anxiety about the uncertainty of their future. Although within the discourse of hope the expression of fear is devalued, admitting to being anxious is even more devalued. Two informants disclose their 'fear' of the unknown. These informants indicate that they can cope with anything as long as they know what is going on. One informant, Betty speaks about her anxiety in terms of not knowing what might happen to her since, at the time of interview, her treatment has not been successful

7.68 Betty: It's the not knowing. You see I can deal with anything as long as I know what I'm dealing with.

Interviewer: Right. And is some of the fear attached to that, not knowing?

Betty: It's the not knowing — and that's, I think you've hit it, that's the biggest fear ... a fear of the unknown. (Betty, l 1657-1676)

The other informant speaks about her experience of waiting for results about her diagnosis. She had been referred to a medical specialist and was awaiting for a consultation. She explains:

7.69 Jan: I might say that I was packing it during this time [said with a great deal of emotion]. Controlling it very well on top, but it was like the not knowing.

Interviewer: You mean fear?

Jan: Yeah. The fear of not knowing. When I know what something is, it's like I can cope with it better than when I don't know what it is. (Jan, l 452-462)

A third informant discloses that she was extremely anxious about knowledge she thought the medical staff may have that they wouldn't pass on to her. When asked to clarify what she feared Martha responds with:

7.70 Oh everything — of their [medical staff] knowledge that they don't pass [on]. (Martha, l 1039-1040)

This anxiety plays a crucial role in Martha's experience of living with a life-threatening form of cancer and stems from a failure to clarify which of the two different interpretations were being used for the word "borderline". Martha began her illness narrative by talking about her diagnosis of ovarian cancer and immediately raises this conflict:

7.71 They diagnosed me as ovarian cancer. That's what I've been told — it was ovarian cancer but it had spread to the — to the borderline of my bowel. I was not told at the time how severe it was or anything like that; it was just

borderline. And I kept asking, ‘What’s the meaning of borderline?’ You know, in your nursing career you work with people all your life and you get more fearful because you got it and of course this borderline — they kept saying, “It’s borderline”. No one saying — no explanation. (Martha, l 3-16)

The word “borderline” has two distinct meanings in this extract. No doubt the medical staff used the word to mean that the cancer was on or near the boundary of the bowel. However, Martha obviously interpreted the word to mean “uncertain or indeterminate”. That is, she thought she was being given conflicting information: on the one hand being diagnosed with ovarian cancer and then believing she was told that the disease was uncertain or indeterminate. Martha’s persistent attempts to clarify the meaning of the word met with the medical staff constantly telling her that they had informed her many times what was happening. The staff thought Martha was being difficult and uncooperative and constantly wanting “miracle answers”. Martha thought that because the staff kept telling her she wanted miracle answers that they knew more than they were prepared to tell her:

7.72 Martha: They know something; that I don’t know — they know — they don’t want to answer — there must be something wrong.

Interviewer: So you thought they were keeping something from you?

Martha: Yeah. Because whatever we tried to ask, me or my children, was just that, “You want miracle answers”. (Martha l 864-876)

Constructing meaning of the cancer experience

As discussed in Chapter Five beliefs within the common sense discourse of cancer and the discourse of moral culpability support the perception that cancer is a disease that is brought upon oneself for a variety of reasons. However, despite the identification of a number of risk factors, such as carcinogenic substances, there appears to be no satisfactory explanation as to why one individual exposed to a risk factor (e.g., smoking) develops cancer and another individual, also exposed to the same type of risk factor, does not develop cancer (Lowenthal 1996). Consequently, developing cancer appears to be a random event. As individuals progress through their illness experience they interact with other individuals living with cancer and compare circumstances and stories. They begin to realise that some beliefs within these discourses are not necessarily accurate or appropriate. Individuals begin to perceive that even medical science does not have all the answers. For example, when Betty’s mother “blamed” her for not looking after herself and consequently getting cancer (see extract **5.32** page 127) Betty’s response of “Who knows? It happens to anyone” implies that she had come to believe that there was no particular reason for an individual

developing cancer. Another informant, Doris, also having lived with cancer for two years by the time of interview, indicates that she is not really sure what causes the development of her cancer; perhaps it is the result of experiencing considerable stress two years prior to the development of cancer: perhaps it is not caused by anything (see extract **5.35** page 129).

Five of the informants in the cancer sample of the current study attempted to resolve the reconceptualisation of self-image dilemma, posed by diagnosis of a life-threatening form of cancer, by constructing self-images as either lucky, important by making 'history' in some form, having a rare form of cancer, providing assistance to other patients 'following' them, or through achieving personal growth. All these self-images reflect a sense of purpose, responsibility and uniqueness. Developing these self-images can be seen as a response to the stigma associated with being represented in society as different, irresponsible, unhealthy and a loss of a socially acceptable identity. In constructing these positive self-images individuals living with cancer attempt to decrease the social distance between the healthy members of society and the 'otherness' of the seriously ill.

Being lucky

It appears that in response to the randomness of cancer development individuals begin to perceive that 'luck' plays an integral part in their illness experience. Luck is claimed to be involved with the growth of the cancer, treatment, survival, and receiving appropriate support. For example, in discussing her experience with surgery Dulcie states that she was warned about the prospects of the cancer having already spread and that, if that were the case, she would have a colostomy. In detailing what occurred during surgery Dulcie indicates that the cancer had not spread to her bowel:

7.73 It hadn't gone through to the bowel so I was lucky I didn't have that [a colostomy]. (Dulcie, l 137-138)

Another informant recalls that as a result of the delay in her diagnosis the cancer had spread to the bone in her left leg. The impact of this episode and the pain she experienced caused Jan to think about a number of issues including the prospect of losing her leg, quality of life and euthanasia:

7.74 It shattered the bone — uhm -- [deep sigh] which is why I was very lucky I didn't lose my leg [very softly spoken] incredible lucky. It's got me talking about all sort of issues like — quality of life and euthanasia. (Jan, l 954-957).

Informants also speak of luck associated with treatment. On several occasions Dulcie states she thought she was lucky that she did not feel sick during chemotherapy:

7.75 Well I was lucky I didn't get sick with it ... I guess I was very lucky and I didn't get sick ... I was one of the lucky ones that didn't get ill (Dulcie, l 153; 242-243; 437)

Dulcie also considers herself lucky that since she didn't get sick because she was able to continue with the treatment without any form of interruption:

7.76 I never missed a session, which was lucky ... but I was lucky I didn't have to delay any of the treatment. (Dulcie, l 178-179; 238)

Three informants also speak about luck associated with surviving. One informant, Josie, who has lived with life-threatening cancer for twenty eight years, thinks she has been lucky to survive:

7.77 I've been lucky. I've been very lucky I've been given a lot — I've had a lot of chances for living and — probably I'm more lucky than a lot of people. (Josie, l 1111-1117)

The other two informants speak in terms of perhaps not being so lucky if the cancer began to spread:

7.78 It could come back and this time I may not be so lucky. (Doris, l 786)

7.79 I mightn't be so lucky next time if it comes up somewhere else. (Sue, l 318)

Two informants speak of luck being involved in gaining appropriate support from family and friends. One informant states that she is lucky that her family provided support for her after surgery. She thought she was particularly lucky that her ex-husband assisted her by giving injections as necessary:

7.80 I think I was one of the lucky ones. He [ex-husband] helped with the needles. (Doris, l 306-307)

Jan also indicates that she believes she is lucky that she has appropriate support from friends:

7.81 ... I am lucky that — none of them [friends] are the sort that really push themselves onto me at all. (Jan, l 1920-1921)

Being important

As a random event the development of a life-threatening form of cancer also appears to have no meaning. Furthermore, patients often perceive that being subjected to the medical gaze during the diagnostic and treatment processes can be dehumanising. They are often required to participate in a number of activities that are out of the ordinary such as allowing strangers to investigate intimate parts of their body; routinely discussing personal or sensitive aspects of their lives; giving up control of their environment and parts of their lives; participating in treatment procedures that may surgically disfigure them, make them violently ill or alter their physical appearance either temporarily (e.g., hair loss) or permanently (e.g., weight gain, deafness, numbness of limbs, kidney damage (Lowenthal 1996)). As discussed in Chapter 6 individuals frequently perceive they are being treated as a case rather than a person. However, analysis of individuals' narratives reveals that there are a number of ways in which the illness experience is constructed as being meaningful for the individual: the most frequent being that through the cancer experience an individual's life has a measure of importance. This sense of importance is gained through either making some form of 'history', having a 'rare' experiences or providing assistance to other patients.

Making history

Two informants discuss their illness experiences in terms of making history: being the first to receive new treatment procedures' and, having journal articles written about them. For example, Josie speaks with considerable pride of being part of history by being the first patient to receive laser treatment:

7.82 I had laser surgery. I was the first one at ... [named hospital] to ever have laser. I had to wait for them to get -- a bed — and in the end they couldn't use the bed — wasn't right for me — so they did the laser without it. (Josie, 1 1322-1326)

Josie also speaks with considerable pride about being the subject of two articles in the *Australian Medical Journal*. She recalls that there was only minimal information available about Bowen's disease when she was first diagnosed in the late 1960s. Josie speaks with a sense of purpose as she details how during her first surgery the cancerous cells were painted different colours to depict the different stages of the surgical treatment. Josie also took great pride in being able to help medical students learn more about the disease.

7.83 I've made the Australian Medical Journal twice, in Queensland — they took — when they first found that I had Bowen's disease ... it helped a lot of people — it helped a lot of young doctors to learn — over the years — for my first lot, doctors didn't know a lot about it, so -- *by them doing that [photographs and journal article] it leaves a record there for ever and ever* — so doctors can go back — and they learn by that — and it helps the medical students ... because if they don't have people like me that will let them learn, well they can't help other people. [Emphasis added] (Josie, l 1344-1390)

Implicit in the emphasised phrase extract is Josie belief that, in a sense, she has achieved some form of immortality. Although she was not identified in the articles, one aspect of her life will live on in the photos and text and, in some way, her life will be perpetuated. This sense of immortality was also implied in her disclosure that her photograph appeared in the hospital's annual report and she was featured in a fund-raising advertising campaign pamphlet.

Rare experiences

Another form of constructing the illness experience as a demonstration of individual importance or uniqueness is making the claim that their experience or form of cancer is either rare or worse than the experiences of other patients. For example, Josie implies that her surgical treatment was worse than others because the doctors discussed her 'case' for the longest period of time:

7.84 I was told by ... [social worker] that they [doctors] had other cases to discuss but mine was the most discussed — because it was the biggest — they wanted to do what was right for me. (Josie, l 1191-1195)

Other informants makes similar claims;

7.85 I had cancer of the clitoris, which is very rare. It only happens thirty times a year in ... [named capital city] and usually in older women of seventy or eighty. (Doris, l 17-23)

In this extract Doris is making a dual claim concerning the rarity of her diagnosis of cancer. Firstly, it is only diagnosed in a very small number of women each year. Secondly, this form of cancer usually occurs in women 20-30 years Doris' senior.

7.86 It's one in a hundred women cancer victims get it I've got the vilest [form of cancer] you can get apparently I've got this rare cancer. They don't know what causes it. (Sue, l 9; 63; 215-216)

Claiming to have a rare form of cancer can be viewed similarly to the externalising of the stimulus for fear. Individuals may be providing themselves with a possible way of avoiding

culpability for not being positive enough. If the cancer is rare, it is likely that there is little knowledge available about it or its treatment. Consequently, the worsening state of the disease, or the individual's eventual death, is out of the individual's control. It is medical science's lack of knowledge about the particular form of cancer and its treatment that is 'culpable' rather than the individual not maintaining a sufficiently positive attitude to fight the disease.

Helping others

Some individuals make meaning of their illness experience in passing on any knowledge and assistance they can to other patients. For example, the theme of helping others is woven throughout Josie's narrative. At every available opportunity Josie assists other cancer patients. For example, she states:

7.87 Every time I go into hospital the stomal therapist gets me to help other people — that are having — colostomies that don't understand them — she gets me to talk to them — show them my colostomy so that they're not frightened — they will know what to expect afterwards ... I just feel [good] if I can help other people to cope with it. (Josie, l 119-1138)

7.88 It is very important for me to give other people — the hope and understanding of cancer — well the hope — that things will be better for them. (Josie, l 1718-1720)

This theme of helping people also appears in Josie's episode of the journal articles. She is very proud of the fact that medical students will not only learn from her experience but be able to help others because of what she has lived through.

Josie "helps" patients in other ways too:

7.89 I'd been out on the balcony and I'd said prayers and I just said to God, "Look that woman's suffered, you know, she's had hell on earth. Surely to God it's time she went to heaven." And that was about twelve o'clock in the night I was out there — having a smoke and talking to Him because I just felt that the woman had suffered just so much that — how much can one person take is what I was thinking — and she died at half past one (Josie, l 1520-1531)

In this extract Josie implies that she believes these two events, her prayers and the patient's death, are connected. Her sense of importance is such that she believes she can negotiate divine intervention on behalf of other patients.

Personal growth

One informant constructs her illness experience as an opportunity for personal growth and her illness narrative is full of incidents that she interprets as offering her opportunities to learn about herself:

7. 90 I was a person who liked every thing being done in a hurry — which is another thing cancer's taught me But each one [problems that arose during diagnosis and treatment] seemed more and more of a teacher. (Jan, l 920-921; 1005)

Although Jan states that previously she pushed her emotions away in order to maintain a positive attitude (see extract **5.62** page 140) she also indicates that because of her prior experience with a personal development course she began to interpret her illness experience as a part of her personal journey:

7. 91 I was on this [personal] journey before [the cancer] but it's like intensified with the illness ... like illness is a teacher. (Jan, l 1785-1793)

As her “journey” through her illness experience progressed Jan says she was able to experiment with experiencing her emotions. Toward the end of her diagnostic process, that continued over a two year period, Jan discloses that she began to allow her emotions to surface:

7. 92 But this time it was more like I was prepared to be a little out of control for a while, allowing myself more to have my emotions. And actually that grew over the time with the experience of cancer ... this willingness to let what my feelings were at that time, have relevance. (Jan, l 483-491)

Through perceiving her experience as a personal journey and attributing ‘lessons’ that she needed to learn for her personal growth, Jan was able to come to acknowledge that she thought her death from cancer was inevitable. She indicates that:

7. 93 I could die tomorrow. I'm perfectly happy. And it's like I've come into an acceptance of myself. I've come to an acceptance of the cancer. 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. (Jan, l 1773-1780)

Summary

As individuals progress through their experience of cancer they begin to realise that some of their personal issues and experiences are not in common with the beliefs and values within the dominant discourses. In particular they realise that beliefs within these

discourses do not encourage the open discussion of strong emotional reactions or thoughts about the future. Consequently, in structuring the beginning of their illness narrative individuals living with a life-threatening form of cancer do so in the socially sanctioned, positive terms of the discourse of hope and the related military metaphor. At the same time they embed verbal and nonverbal symbols in their narrative that indicate that the individual's private reality might be different to the public, socially valued reality initially being presented. These cues also indicate the individual's need and willingness to openly discuss sensitive and emotional issues that are frequently disenfranchised by the dominant discourses. In particular individuals discuss their thoughts about the future and reveal that, in contrast to the discourse of anticipatory grief, fear and anxiety dominate. Although there are some common fears and anxieties, not all individuals experience the same fears and anxieties. Therefore, it is important to focus on what meaning the individual attributes to the various aspects of their illness experience

Disclosure of meaning is not spontaneous and requires the listener to suspend acceptance of beliefs within the dominant discourses and to explore the patient's discourse. Fear is the dominant discourse associated with individuals' subjective experience of living with a life-threatening illness. This fear is predominantly focussed on aspects of the individual's future. Disclosure occurs at any one of three levels. The first level disclosure is voluntary and involves a basic social description of the individual's fear. Second level disclosure involves the individual identifying the cause of their fear and often involves more emotional expression. Third level disclosure rarely occurs spontaneously and involves the individual's identification of the meaning of their experience. It requires an environment in which the individual believes that their explanations will be accepted and valued. Furthermore, it requires an effort from the listener to not only refrain from imposing socially accepted ideas and values on the individual, but also active exploration of the individual's comments and checking conclusions with the speaker. This level of disclosure frequently includes beliefs that are contrary to those of the dominant discourses.

As an apparent reaction to the random nature of the development of cancer, the dehumanising nature of the medical gaze involved in the diagnostic and treatment processes, and the social distance between healthy members of society and the otherness of the seriously ill person, individuals construct their illness experience in a number of

meaningful ways. These newly conceptualised self-images include being lucky, being important through making history in some way, having a unique or rare experience, or helping others and perceiving their illness experience as involving personal growth.

The following two chapters will discuss the issues associated with HIV/AIDS.