

Chapter 10

Conclusions

Introduction

Previous research has continued to accept the validity of anticipatory grief despite its limited conceptual and empirical foundation (Siegel & Weinstein 1983). The continuing quest to identify the phenomenon's benign, adaptive or harmful consequences on the resolution of grief has resulted in the accumulation of inconsistent and inconclusive findings (Rando 1986a). Notwithstanding this lack of clarity, the concept continues to have an enduring appeal for clinicians. Siegel and Weinstein (1983) suggest that belief in a process which can mitigate the impact of ultimate death may reduce the personal feelings of helplessness and vulnerability experienced by health care professionals working with dying patients and their significant others. Widespread acceptance of the concept may be similar to a self-fulfilling prophecy: popular recognition of the concept is taken as prima facie evidence of its existence, which leads to its adoption by other clinicians and, in turn, this leads to more general agreement on the concept's existence. In addition, when confronted with clients facing an impending death, clinicians may observe what they expect to observe: commencement of the grieving process in anticipation of the loss (Siegel & Weinstein 1983). However, there have been no attempts to empirically validate the concept.

It has been claimed that what occurs for individuals anticipating a loss is a complex subjective experience that is not particularly amenable to quantification (Fulton & Gottesman 1980; Rando 1986a). Rando (1988) further argues that the term anticipatory grief is a misnomer but the phenomenon exists as a complex amalgam of the processes of mourning, coping, interaction, planning and psychosocial reorganisation stimulated by the awareness of an impending loss. This broadened the 'phenomenon' from the more commonly accepted definition as any grief occurring prior to an actual loss (e.g., Ball 1977; Hill et al. 1988; O'Bryant 1990-91; Sweeting & Gilhooly 1990). The current research supports these authors' claims concerning the complexity of the issues associated with anticipating a death and, in supporting, authors who refute the existence of anticipatory grief

on definitional grounds (e.g., Glick et al. 1974; Parkes & Weiss 1983; Silverman 1974), found that individuals' imagined futures focus on dreaded issues or events and not anticipated losses.

The major problems with prior research into anticipatory grief, identified in the review of literature in Chapter Two, were: the continued belief in the assumption that the phenomenon exists; grounding research in the positivist framework that does not allow for the possibility that the period of anticipating a significant loss might have different meanings for different people; the collection of retrospective data only; and, the failure to include individuals who are facing the impending loss as participants in the research. The current research addressed these issues in an innovative way. Firstly, it used social constructionist theory to examine how individuals responded to knowledge of their impending death, how this impacted on their experience of living with a life-threatening disease and, in particular, how they constructed their imagined futures, the focus of these ideations and the responses they elicit. Secondly, it collected data from individuals who were actively engaged in the process of facing their own impending death. This led directly to the third issue, the collection of two types of data concerning individuals' thoughts about their future. Retrospective data was gathered about how individuals conceptualised their future at various times prior to interview (e.g., at diagnosis and during treatment). During the interview current data was compiled on how individuals currently conceptualised their future. In essence, the current research investigated the conceptual validity of anticipatory grief. A further innovation in the current research was the investigation of two different diseases rather than reliance on the most commonly used single disease - cancer. As will be discussed below, the most valuable contribution arising from investigation of two diseases is clarification of the traditional interpretation of 'why me?' type questions: These questions indicate a crisis of self-definition rather than symbolising the expression of anger.

Using the theoretical framework of symbolic interactionism to examine the issues associated with individuals facing impending death advances current knowledge by providing a different focus on the problem. A fundamental assumption of symbolic interactionism is that a number of realities exist, namely an objective reality, a social reality and a subjective or personal reality (Charon 1992). A physical reality exists independently of the number and variety of social definitions applied to it. Similarly, the existence of a

subjective reality does not necessarily depend on the dominant social definitions applied to the physical reality. Another important assumption of symbolic interactionism is that the meaning of social objects does not develop in isolation but through routine social interaction between and among individuals. Furthermore, during this interaction, individuals change the meaning of objects, notice new objects or ignore initially used objects depending on the action in which they are involved and the needs they have in achieving their goals (See Chapter Three). Applying symbolic interactionism to the issue of anticipatory grief acknowledges that the period of anticipating loss through death is not static and may have multiple meanings. It also facilitates the identification of multiple realities which are based on different community groups' application of variations in definitions to the same illness-related social objects. In using the theoretical paradigm of symbolic interactionism this thesis has demonstrated the existence of an experiential discourse that categorises, structures and develops meaning of the subjective experience of living with a life-threatening illness (see Chapters 7 and 9). This discourse has developed in response to individuals' perception that the common sense and medical discourses do not accurately reflect the actual experiences and meaning of living with a life-threatening illness.

The purpose of this chapter is to discuss the current research's contribution to knowledge of anticipatory grief, present a summary of the major research conclusions, discuss the implications for health care professionals, the limitations of the study and an agenda for future research.

Contribution to current knowledge

The major contribution of the current research is that it has responded to the issue of conceptual confusion raised by a number of researchers (Fulton & Gottesman 1980; Rando 1986a; Siegel & Weinstein 1983; Sweeting & Gilhooly 1990). In using a different theoretical paradigm it has clarified the concept of anticipatory grief by identifying the focus of individuals' imagined futures, what triggers these thoughts and the emotional response they engender. As will be discussed below the research has recognised the existence of an experiential discourse used by individuals living with a life-threatening illness. This discourse is marginalised by both the common sense and medical discourses. Furthermore, the current research has identified the importance of understanding

individuals' personal context when interpreting symbols they produce: an extension of Averill's (1968) concern regarding the importance of understanding the social context in which ambiguous behaviour (e.g., crying) occurs. Finally, in examining the responses to two different diseases the current research found evidence to contradict the traditional explanation of "why me?" questions symbolising the expression of anger. As will be discussed below, these questions indicate a crisis in self-definition that is associated with the uncertainty surrounding the cause and prognosis of some life-threatening illnesses.

The innovative features of the current research prevents the drawing of comparisons with the empirical studies critiqued in Chapter Two. The major difference centres on the assumption concerning the existence of the concept. The critical question guiding previous empirical work was not whether the concept existed but whether it was psychologically useful in mitigating the post-mortem grief of the survivor (Clayton et al. 1973). More recently, Rando (1986a) has claimed that the primary justification for the study of anticipatory grief lies in its unique opportunity to provide an arena for primary prevention. In practice, prior research (e.g., Ball 1977; Binger et al. 1969; Gerber et al. 1975; Hill et al. 1988; O'Bryant 1990-91) focussed on attempts to identify, or measure (e.g., Levy 1992; Welch 1982), the effects of a theoretical 'syndrome' that has not been empirically substantiated. It has been claimed (e.g., Rando 1986a) that in relation to anticipatory grief the issue is a matter of semantics rather than clarifying inherent conceptual issues. However, clarification of conceptual issues is vital as it is the conceptual structure that provides the foundation upon which to pose the appropriate empirical questions and, ultimately, support the development and implementation of effective therapeutic interventions.

In contrast, the current research did not perpetuate these equivocal practices. Conversely, it focused on the problem of conceptual clarification by identifying how individuals actually living with a life-threatening illness construct their imagined futures and how they interact with these projected ideations.

Summary of conclusions

The major conclusions arising from the study are provided in statement form followed by a brief discussion.

Influence of common sense discourse

The definition of the situation and configuration of meaning delineated by the common sense discourses of cancer and HIV/AIDS influences individuals' initial interaction with all personally unfamiliar social objects associated with each disease.

The current study found that in discussing their initial responses to the multiplicity of unfamiliar subjective experiences, associated with personal diagnosis and treatment, individuals reflect the complex interaction of the common sense discourses of each disease, death, culpability, stigma, pain and hope. The most prominent beliefs individuals refer to are associated with the life-threatening nature of each disease: death as the ultimate outcome of each disease, when death will occur, the illness experience leading up to death and the 'expected' ways of responding to the disease and illness experience. These particular elements of the common sense discourses have a major influence on how individuals symbolically designate other personally unfamiliar, illness-related social objects. For example, post diagnosis development of other physical symptoms are initially perceived as symbols indicating the inevitable, progressive deterioration of the disease.

The importance of these particular elements of the common sense discourses resides in the qualitative difference between perceiving the world through the social reality constructed via these elements and their impact on the subjective reality of the illness experience. More precisely, prior to their own diagnosis individuals accept the common sense discourse as a way of describing and categorising the physical and social worlds of cancer and HIV/AIDS. The symbols (e.g., patterns of words, figures of speech, concepts, and values) that constitute these discourses, are perceived as objective truths that establish the physical and social reality of each disease and are beyond human intervention. As members of the community who use these common sense discourses, individuals do not question the validity of this socially defined reality to explain the specific disease and illness experiences. Since these common sense discourses provide a definition of the situation and configuration of meaning concerning cancer and HIV/AIDS, individuals believe they accurately reflect their future experiences. When faced with the variety of personally unprecedented illness-related social objects, individuals have no alternative way of describing and categorising their personal experiences. They depend on these commonly

understood and accepted social descriptions and categorisations of these diseases, and the subsequent illness, to understand and make meaning of their subjective experience.

In response to their own diagnosis, and all new subsequent disease-related experiences, individuals organise their own conduct and their expectations of others based on the definition of the situation and configuration of meaning delineated by these common sense discourses. They apply the social reality to their subjective experience: The socially held belief that each disease is a death sentence converts into the personal realisation that “I am going to die!”. Furthermore, it is a commonly held belief that death will occur within a limited time period: For those individuals diagnosed as being HIV-positive the commonly accepted belief was that death will occur within a matter of weeks or months, whereas for individuals diagnosed with cancer, death will result in a matter of “six months” to “a couple of years”. (With the development of further knowledge concerning its progress, HIV/AIDS is currently perceived as a chronic illness with a life span of more than ten years from diagnosis (Chaisson 1990).) In addition, it is commonly believed that this death will occur in specific ways: through physical wasting and development of dementia for individuals with HIV/AIDS and painfully for individuals with cancer. These latter beliefs are personalised to the dreaded event ‘I will physically waste away and develop dementia before I die’ and “I will die a painful death”.

Conflict between social definitions of reality and subjective experience

There is conflict between the social definitions of reality, as provided by the common sense discourse and individuals' interpretation of the medical discourse, and individuals' subjective reality. Individuals also perceive that there are a number of conflicting beliefs within the medical discourse.

It is apparent from the current research that applying social understanding to their personal circumstances of a life-threatening illness confronts individuals with a number of common dilemmas. The most difficult dilemmas are associated with the task of reconceptualising their self-images. One of the principal self-images challenged by diagnosis of a serious disease is that of being a healthy, socially responsible member of the community. Medical diagnosis simultaneously defines individuals as physically and socially unwell. Reconceptualising this previously held ‘positive’ self-image to the less socially acceptable

'irresponsible, unhealthy other' can be an exceptionally difficult task, particularly in the absence of accepted symbols (e.g., a variety of symptoms) that indicate the existence of a disease. When the serious disease is one of a life-threatening nature individuals are confronted with the simultaneous challenge of reconceptualising their self-image to one of a person facing the reality of their own mortality and impending death. This task is further exacerbated by the commonly accepted beliefs, within the common sense discourses, about poor prognosis.

The difficulties confronting individuals reconceptualising their self-images are exacerbated by the fact that common sense discourse beliefs about ill health are often expressed in a constellation of metaphorical systems (Lupton 1994a) that frequently make moral judgements about the individual and are often perceived as ways of taming or defeating death (Sontag 1991). One of the most powerful metaphors that dominates modern medical and health discourses, that deal with life-threatening and infectious diseases, is the military metaphor (Lupton 1994a). This metaphor supports the belief that 'winning' the 'war' against cancer, and prolonging life with HIV/AIDS, is intimately linked with the maintenance of a positive attitude to all aspects of the disease, treatment and illness experience. This metaphor is intertwined with the discourse of hope which emphasises the need to have enough willpower to change the course of disease in the body (Good et al. 1990), to 'defeat' the 'enemy' and 'recapture' a healthy physical and social status. Individuals are deemed responsible for their ill health (e.g., through injudicious exposure to carcinogenic substances, excessive stress, inappropriate personal and dietary habits and sexual preference). Also, they are held responsible for maintaining a positive attitude at all times. The recently diagnosed individual with cancer quickly learns that those who appear 'brave' in the face of the disease and illness experience, who never allow themselves to 'surrender' to the disease, are extolled (Lupton 1994a). Individuals living with a life-threatening disease perceive the 'requirement' to be positive at all times as a sanction against expressing their often overwhelming 'negative' emotions. This creates considerable emotion confusion for individuals as they struggle to contain the intensity of their emotional responses, while responding in the positive ways expected by beliefs within the dominant discourses. These individuals also perceive that neither the common sense discourse nor the medical discourse provides effective avenues for them to discuss or

resolve, with significant others, their strong emotional reactions to the disease and illness experience.

At diagnosis individuals engage in social interaction with members of the medical community. For individuals with cancer, this new social interaction is particularly important as it introduces them to ways of classifying and categorising the social objects, associated with the disease, that differ from those used within the familiar common sense discourse. For example, hair loss resulting from chemotherapy defined as 'horrible' or 'undignified' within the common sense discourse is redefined by beliefs within the medical discourse as a 'minor' side effect and a 'small price to pay' for extending life. In turn, interaction with health care professionals raises further dilemmas for individuals. They are confronted with incongruencies between the common sense and medical discourses: cancer is not perceived as a 'death sentence' within the medical discourse and consequently individuals are encouraged to maintain 'hope' to 'win' the 'battle' against the disease. Through interaction with different members of the medical community (e.g., general practitioners, specialist surgeons, oncologists and nursing staff), individuals are introduced to conflicting information within the medical discourse: Medical professionals have varying views on causes, treatment and prognosis of cancer.

The situation differs for those individuals diagnosed as HIV-positive. During the early years of the disease there was little difference between the common sense and medical discourses of HIV/AIDS. A common response from individuals in the HIV/AIDS sample is that since medical science has not developed a cure there is little point in maintaining an intense interaction with the medical profession. An early belief within the common sense discourse of HIV/AIDS was that individuals would inevitably die within a relatively short period after diagnosis. However, when individuals' initial symptoms subside, or they survive longer than that indicated by the common sense discourse, they begin to question the validity of these commonly held beliefs. By indicating that they 'hope' to be the first person to 'beat' the disease informants demonstrate that they are influenced by the discourse of hope and the military metaphor.

Distancing self from the common sense discourse

Individuals living with HIV/AIDS are able to symbolically distance themselves from the effects of the common sense discourse more effectively than their cancer counterparts and hence challenge the power of this discourse.

A major difference between the discourses of each disease is the availability of knowledge concerning a variety of aspects of the diseases. Treatment of individuals diagnosed with cancer is aggressive (e.g., chemotherapy) and often invasive or destructive (e.g., surgery and radiotherapy). Throughout treatment individuals are constantly interacting with members of the medical community and influenced by the medical discourse. The limited time between diagnosis and treatment often does not allow individuals sufficient time to give consideration to the impact of diagnosis or recommended treatment. Once diagnosis is sought and confirmed individuals find it very difficult to step off the medical 'treadmill'. It often appears to these individuals that various treatment regimes are developed and implemented with extreme haste in an effort to halt the 'invading' forces of cancerous cells. Although given information about treatment, individuals perceive that there is no time to lose in consenting to treatment and, under these conditions, little time to consider implications of treatment. Consequently, it is difficult for them to 'distance' themselves from either the common sense or medical discourse of cancer and avoid the imposed identity of the 'other' with its sense of culpability. Also it is more difficult to challenge the power of these discourses.

Individuals appear to submit to this treatment because of their strong desire for medical science to provide a cure and enable them to ultimately 'defeat' death. This focus on overcoming the effects of the disease and avoiding death overrides individuals' ability to comprehend the emotional aspects of aggressive treatment. Without prior personal experience, individuals are temporarily influenced by the medical community's definitions of social objects. Because it offers the hope of medical cure, treatment is perceived as 'life-saving', 'essential' or 'the only alternative'. Despite being informed of the 'negative' implications of treatment, it is not until some time after the event, when individuals have had ample opportunity to consider the emotional impact of 'life-saving' treatment, that they

begin to redefine the social objects of surgical treatment, chemotherapy or radiotherapy to 'disfiguring' or 'mutilating'.

How individuals redefine these social objects appears to depend on their perspective on life. For example, two middle-aged, cancer informants underwent the same surgical procedure: a vulvectomy. However, their responses to this surgical treatment differed considerably. One, who perceived herself to be a 'fighter' appeared to 'take it in her stride' and did not perceive it overly influencing her self-image as a 'complete' woman who was able to engage in personally satisfying sexual relations. The second person initially influenced by the positive aspects presented by members of the medical community responded with humour saying that the effects of surgery would not adversely affect her as she had decided "not to use the equipment anymore anyway". The implication in this comment being that a body part that was not being fully utilised would not be missed. However, after the event, when she was confronted with the emotional effects of the surgery, she began to redefine the treatment from 'life-saving' to 'disfiguring'. This 'disfigurement' began to influence her self-image as a woman. Prior to surgery her concept of a 'complete' woman not only included the presence of intact genitalia, but also what this represented: the ability to engage in "close, intimate relationships". However, post-surgery she reconceptualised her self-image to that of not being "complete anymore, and you're not a woman". Despite reassurances from members of the medical community that she was still a woman she was not convinced and believed that health care professionals "haven't lost it so they don't really understand".

The situation is very different for individuals living with HIV/AIDS. Individuals challenge the applicability of the common sense discourse to their own experience by using any one, or a combination, of three methods of physically or symbolically distancing themselves from the concept of the 'other'. The methods identified in the current research are a) creating symbolic distance, b) focusing on the experiences of friends, and c) focusing on living. The absence of a medical cure for the disease and intense interaction with the medical community enabled individuals to utilise these methods. Without the prospects of a cure individuals did not seek the same quality of aggressive medical intervention as did their cancer counterparts. Distancing themselves from the dominant discourses is not a form of denial. All individuals in the HIV/AIDS sample acknowledged that they were

infected with the virus and at the same time used the distancing strategies mentioned previously to enable them to 'get on with life'.

Engaging the medical discourse

Individuals living with cancer engage the medical discourse either actively or passively and assess the quality of their interaction with members of the medical community based on their interpretation of health care professionals actions. Individuals living with HIV/AIDS did not raise the issue of did not engage the medical discourse in the same way as their cancer counterparts.

The current study found that there appeared to be differences between the two samples in how individuals engaged the medical discourse. Whereas individuals living with HIV/AIDS spent little time discussing interaction with the medical profession, individuals living with cancer devoted considerable amount of their narrative to discussing their interpretation of the medical discourse.

Individuals living with cancer engaged the medical discourse either actively or passively. Active engagement involves seeking information about the disease, its treatment and course. The quality of this interaction is dependent on individuals' interpretation of the action of others. If the action is interpreted as symbolising interest in their experiences, individuals identify the interaction as positive. The answering of questions is interpreted as symbolising personal interest and results in individuals believing that interaction with the medical community is positive. Alternatively, if the action of others is interpreted as symbolising disinterest in their experiences or concerns individuals identify the interaction as 'negative'. Providing inadequate answers to their questions or not providing appropriate information is interpreted as symbolising disinterest and lack of concern.

Passive engagement of the medical discourse consists of patients, who have already been through some form of treatment, being 'recruited' by medical staff to act as 'treatment ambassadors'. These patients are requested by medical staff to talk about their treatment experiences to other patients who have a similar disease and may have not yet decided to agree to further treatment or who may be contemplating relying on 'alternative' therapies. In talking to other patients these treatment ambassadors reinforce the medical discourse in

two ways. Firstly, they 'teach' the medical discourse to fellow patients, particularly the 'positive' aspects concerning treatment. Secondly, they also reinforce elements of the medical discourse for themselves.

Acting as a treatment ambassador can place individuals in an ambiguous situation. By speaking to other patients they are perceived as a 'role model' or goal for patients to strive to achieve: successful completion of treatment. In some respects they are presented to other patients as symbolising the average patient and, simultaneously, 'set apart' from the average patient. At the same time individuals acting as treatment ambassadors perceive themselves as having a closer relationship with the medical team. However, acting as a treatment ambassador does not gain any 'privileges' with members of the medical team: when seeking information, from members of the medical team, concerning the progress of patients with whom they have been requested to interact as treatment ambassadors they are treated as another patient who does not have the 'right' to this 'confidential' information.

Social and personal responses

Individuals initially present their illness experiences in the socially expected ways defined by the common sense discourses, but embed symbols in their narrative indicating the presence of a different, subjective reality and their need to discuss, and have others validate, the meaning of their subjective experiences.

The current study produced evidence to support the claims of previous researchers (e.g., Bor & Miller 1988; Siegel & Weinstein 1983) that health care professionals have difficulty discussing highly emotive issues with patients. As noted previously, the definition of the situation and the configuration of meaning provided by the common sense discourses associated with life-threatening disease and illness serves as a framework for social actors to organise their own conduct and their expectations of others. Individuals interpret the actions of many other members of the community as symbols indicating a lack of preparedness to discuss highly emotional and death-related issues. This perception is based on their interpretation of the practices associated with both the common sense and medical discourses. On hearing of the diagnosis some family members and many pre-illness friends regularly avoid social interaction with the individual. Persons living with the disease interpret this behaviour in a number of ways that supports their belief that healthy

individuals can not cope with the emotional aspects of the illness experience. Individuals believe that health care professionals also avoid this type of discussion through the practice of selectively responding to their concerns or questions.

In discussing their illness experiences in socially expected ways, individuals embed symbols indicating their need to discuss, and have others validate, the meaning of their subjective experiences. Disclosure of subjective experiences and meaning is influenced by whether the individual perceives the listener is interested in hearing the subjective experience and 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, individuals living with HIV/AIDS were particularly wary of disclosure of their health status because of their perception that other people reject them because of the disease rather than personal qualities.

Disclosure of personal meaning

Disclosure of meaning of highly emotive issues does not occur as 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 individuals comfort with such disclosure and their assessment of whether their responses will be accepted and not devalued.

The current study found that individuals embed symbols in their narratives that indicate the presence of a subjective reality that differs from the socially defined of the dominant discourses. These embedded symbols indicate a need to discuss these personal realities and meanings. However, when these embedded symbols were either ignored or misinterpreted by members of the medical community individuals frequently deferred to the health care professionals' 'superior' knowledge and understanding. This action supports Foucault's concept of power relations. Individuals believed that the health care professional 'must know better' and so rejecting their own interpretations of their emotional responses. For example, if a member of the medical community interpreted individuals' tears as symbolising grief and responded accordingly, individuals acquiesced and, while interacting with the professional, agreed to his assessment. This occurred despite individuals perceiving that they were feeling frightened or anxious. However, when embedded symbols were openly acknowledged individuals' experiences are validated.

Embedded symbols are the first level of disclosure which is voluntary and involves description of experiences in general, socially accepted terms. When these embedded symbols are acknowledged individuals begin the process of disclosing the personal meaning of illness. Second level disclosure occurs when the individual identifies the cause of their emotional response and often involves the expression of emotion. This level of disclosure may be spontaneous or in response to the listener's clarifying questions. Third level disclosure occurs when individuals identify various aspects of the meaning of their experience. This level of meaning rarely occurs spontaneously. It requires an environment in which individuals believe that their explanations or comments will be accepted, valued and validated.

Experiential discourse

Individuals living with a life-threatening disease use a different discourse that categorises, structures and develops meaning of the subjective experience of living with a life-threatening disease and illness. This 'experiential' discourse has developed in response to the perceived inadequacies of the dominant discourses to reflect actual experiences.

The current research found that in attempting to resolve the perceived inconsistencies within the medical discourse, the conflicting beliefs between the common sense and medical discourses and between the socially defined reality of living with a life-threatening disease and personal experiences, individuals turn to others who have been through, or are going through a similar experience. A sense of camaraderie develops between individuals or groups sharing similar experiences. Individuals frequently find the mutual support to discuss emotionally sensitive issues that they perceive can not be discussed with family, friends or health care professionals. These issues include their fears and anxieties about all aspects of the disease and illness experience. Many individuals living with a life-threatening form of cancer talk about the strength of continuing friendships initiated and forged through their common cancer experiences. However, this is not always the case and some individuals avoid further contact with former patients. Although recognising their right to cease contact other patients often indicate that these individuals experienced

difficulty during their illness experience and were not able to deal effectively with the emotional issues raised by their illness. In a sense this is implying that those patients who mutually share their fears and anxieties about their illness experiences are doing so in a 'healthy' way but those who avoid contact with fellow patients are 'unhealthy others'.

Through this new social interaction a shared understanding of, and way of structuring, the experiential world of each disease develops: A new perspective emerges. It is the sharing of these perspectives that confers 'objectivity' to individual patient meanings. Individuals perceive that this 'experiential discourse' validates their subjective experiences. At the same time they perceive this reality is marginalised by adherents of the dominant discourses.

Although believing members of the medical community are trying to provide assistance many individuals perceive that this occurs within the framework of the medical discourse and is not always appropriate to their needs. In essence two slightly different and competing discourses are being used. Therefore, there are two competing definitions of the situation and configuration of meaning. This results in two slightly different frameworks for social actors to organise their own conduct and their expectations of others. The same social objects are given different symbolic designations. When a symbol is provided by a member of one social group it is likely to be interpreted in the slightly different way by a member of the second group because it has a slightly different meaning. For example, crying is a symbol that has multiple meanings. Within the professional discourse of grief, crying is often perceived by the observer as symbolising an individual's expression of grief (Parkes 1986; Raphael 1985; Stroebe & Stroebe 1987; Stroebe, Stroebe & Hansson 1993). This professional perception is supported by research such as Clayton et al. (1968) who argue that crying is one of only three symptoms of bereavement. However, other researchers (e.g., Averill 1968; Mishler 1979) suggest that the context of the behaviour must be considered when interpreting its meaning. The action of crying can symbolise many things (e.g., grief, sadness, relief, joy, fear or anxiety). The context of the behaviour provides further indicators of the specific meaning of crying behaviour. Averill (1968) provides the example that a woman crying may not be a sign of grief: she may be weeping for joy, relief or in physical pain. However, a mother crying at the death of her child would be judged as an expression of grief.

Results from the current study extend Averill's (1968) claims by suggesting that the individual's personal context, in which the crying occurs, is an important aspect of the situational context. To the member of the medical team, who accepts the professional discourse of grief and observes a person who cries during hospitalisation for treatment for a life-threatening disease, crying may be interpreted as symbolising the expression of grief. However, for the individual, who brings a self-image into interaction with the disease and illness experience as being tough and able to cope with anything, crying may be a symbol of fear and anxiety about an imagined future: A future in which she/he is not 'strong enough' to respond to the illness experience as he/she hopes. To effectively understand the symbolic meaning of crying behaviour the observer must be aware that the individual providing the symbol may be using a different perspective within any given situational context. The observer must seek clarification from the individuals: What is prompting this crying behaviour; Is it physical or emotional in origin; If emotional, what is the object to which the individual responds with tears? People react to the symbolic meaning given to objects and these meanings can differ. The observer must remain open to explore the individual's symbolic designation.

Another example from the cancer sample concerns side-effects of treatment. It is apparent that the same social objects, namely physical symptoms, are defined differently by the medical discourse and the experiential discourse. Influenced by the common sense discourse beliefs that cancer is a death sentence and any remission is only temporary, individuals define the occurrence of any new symptoms as symbolising the probable return of the cancer and something about which they should be concerned. However, the medical community defines these symptoms as 'unimportant' or 'minor' in relation to the absence of cancer or 'side effects' of treatment. Patients frequently interpret medical practitioners' action in dismissing these symptoms as symbolising a lack of interest in, and concern for, their welfare.

The main feature which distinguishes the experiential discourse from the dominant discourses is its perspective, or way of structuring the world of life-threatening disease and illness. The medical discourse structures this particular world from the perspective of the group of individuals who seek to eradicate or control disease and its effects on human kind.

The common sense discourse structures this world from the perspective of the members of the community who, without specialised medical knowledge or personal experience, attempt to understand and make meaning of the disease and illness experience. The experiential discourse structures the world of life-threatening disease and illness from the perspective of individuals who have been diagnosed with the disease and involved with the day-to-day experiences of interacting with the disease.

Focus of imagined futures

Individuals living with a life-threatening disease construct imagined futures throughout the illness experience. These constructions focus on a range of 'dreaded events or issues' to which they respond with fear and anxiety.

The anticipatory grief literature reviewed in Chapter 2 suggests that when individuals are facing an anticipated death the focus of their imagined futures is on the range of losses that are likely to occur prior to the event of death. Furthermore, individuals' respond to these imagined losses with grief. However, the current research found that constructing imagined futures is not restricted to the latter part of the illness experience preceding impending death. Imagining a range of possible futures begins with the appearance of initial symptoms and continues throughout the illness experience. Beliefs within the common sense discourses suggest that certain symptoms (e.g., unusual lump, unexpected discharge of blood or other fluids, night sweats and diarrhoea) are indicative of the development cancer or HIV/AIDS. When these symptoms appear, individuals frequently imagine that they have the disease and begin to respond to these thoughts with fear and anxiety. This response frequently occurs prior to undertaking diagnostic tests. In some instances this fear and anxiety prompts individuals to seek diagnostic testing to verify their concerns. Alternatively, some individuals are so fearful of cancer being confirmed that they avoid seeking medical advice or a second opinion until more dramatic symptoms appear (e.g., "collapsing in a pool of blood", foul smelling vaginal discharge of long duration).

The current study found that for informants in the cancer sample fear and anxiety is often present during their illness experience but not always expressed. These 'negative' emotions are often masked or hidden by other, more socially expected responses such as humour or bravery. The discourse of hope encourages individuals to push their 'negative' emotions

aside in order to constantly focus on the 'positive' aspect of 'beating' the disease. Individuals are encouraged to imagine their future as free of the disease. However, in view of the moral authority of the common sense discourse, the central belief that cancer is a death sentence is difficult to ignore and individuals find it a formidable task maintaining a positive attitude.

The current research found that individuals construct a range of imagined futures to which they attribute meaning and with which they interact. These imagined futures, as social objects, have meaning ascribed to them by elements of the common sense discourse. Individuals then react to these commonly ascribed meanings. The current research supports the claims by Bor and Miller (1988) in that it found that these imagined futures consist of a range of dreaded issues or events associated with the illness trajectory, the event of death, and expectations after death, to which individuals respond with anxiety or fear. These dreaded events did not focus on anticipated losses. Individuals imagine themselves experiencing debilitating illness, and are frightened; they imagine themselves alone, and are frightened or anxious; they imagine themselves as dependent on others, and are frightened; they imagine experiencing a "horrible ending", and are frightened.

When contemplating their future informants focus on a range of 'dreaded' events. Some of these dreaded events, such as the illness trajectory, the event of death and post-death 'experience', are common to both samples. Other imagined futures appear to be disease specific. For example, some informants in the HIV/AIDS sample imagine futures in which their family of origin, significant others, or work colleagues obtain knowledge about the individual's health status and reject them. Other informants in this sample construct futures in which they have infected their partner who then blames them for transmitting the infection. The most common imagined future specific to informants in the cancer sample is the probable effects of treatment. The response common to all these imagined futures is fear and anxiety.

Aspects of the illness trajectory most feared are the development of further symptoms which symbolised progression of the disease. Individuals also respond with fear when they imagine themselves not being able to cope with various aspects of the illness experience (e.g., treatment, side effects, pain, needing to rely on others for assistance, dementia). The

most common perception individuals have of themselves in these situations is not being able to 'cope' with the event and not responding in the socially expected way. Some of the HIV/AIDS sample speak explicitly and implicitly about committing suicide should this event occur.

In discussing their 'fear' of the event of death individuals are actually identifying their feelings of apprehension about how their death might occur. For individuals in the cancer sample the most dreaded event is the prospect of dying in pain. This is also a difficulty for an informant in the HIV/AIDS sample who regularly imagines a future in which dementia has developed and his Kaposi's sarcoma has become very painful but he is unable to communicate to his pain relief needs to health care professionals.

Individuals from both samples also discuss the uncertainty of their 'future'. They do not know what the future holds; they do not know what the results of tests will be; they do not know if the medical staff are holding back information; they do not know when the disease will progress further; they do not know when they will die. Individuals discuss their responses to these unknown elements of the future in terms of 'fear of the unknown'. However, since there is a quality of indefiniteness and lack of object in these imagined futures, individuals are actually experiencing anxiety rather than fear (see Freud 1959).

A number of individuals in both samples imagine futures in which, through their death, they are separated from significant others. Individuals discuss these scenarios in the more acceptable terms of being 'fearful' for others, primarily partners or children. However, what individuals are actually discussing is their anxiety about separation from these significant others.

The current research does not suggest that the experience of grief is not present during the process of living with a life-threatening disease. As suggested by Rando (1986a), grief, when it is present, is in response to losses that have already occurred. The situation is best summarised by one of the informants who made the comment "I can't be sad for things that haven't happened yet". This comment also supports the arguments presented by researchers (e.g., Glick et al. 1974; Parkes & Weiss 1983; Silverman 1974) who refute the existence of anticipatory grief on definitional grounds. That is, since grief is normally defined as the

response to a loss, it implies that the loss must precede the expression of grief. Therefore, by definition, the reaction to an impending or anticipated loss can not be grief but some other emotion. The current study found that these emotions are predominantly fear and anxiety.

Crisis of self definition

Uncertainty surrounding the 'cause' of a terminal disease creates a crisis of self definition for individuals and prompts the question 'why me?' Alternatively, certainty about the cause of the disease prompts a different type of question, 'what now?'

The current study found that there appears to be a relationship between uncertainty about the cause of the disease and posing 'why me?' type questions. All informants in the cancer sample, either explicitly or implicitly, posed the question 'why me?' This is done in the context of seeking to understand the cause of their cancer. In contrast, none of the informants in the HIV/AIDS asked this type of question. This difference raises questions concerning the conventional explanation.

Traditionally, the question 'why me?' has been accepted within the professional discourses of dying and grief as a symbol of individuals' expression of anger at their terminal diagnosis or knowledge of the impending death of a significant other (see Kübler-Ross 1970; Rando 1984; Raphael 1985). Knowledge concerning the cause of HIV/AIDS was developed within two years of identifying the new disease. All informants in the HIV/AIDS sample knew that a virus was responsible for causing irreversible damage to their immune system which then enables the development of opportunistic infections that result in death. Informants in the HIV/AIDS sample did not devote any time or emotional energy trying to find a reason for their infection. It was clearly understood by all within the HIV/AIDS sample that, at some time, they had come into contact with the virus through infected body fluid. None of these individuals asked 'why me?' For some individuals the more relevant question was 'how' or 'when' this occurred rather than why. Other individuals were not concerned with either how or when questions. However, all informants in the HIV/AIDS sample, either explicitly or implicitly, posed the 'what now?' question.

However, the situation is very different for individuals diagnosed with cancer. Cancer is an ancient disease and although it was well known to the Greeks two thousand years ago it is not yet fully understood why cancer develops (Lowenthal 1996). This uncertainty is reflected in all the narrative of each informant in the cancer sample. All of these informants invested considerable time and emotional energy to the search for answers to the questions “Why me and not some other person?”, “Why this particular disease?” and “Why now, (at this particular time in life, after what I’ve been through, I’ve been a good person)?” Reasons given by informants reflect the range of beliefs within the common sense discourse and include topics such as exposure to carcinogenic substances (e.g., smoking), various forms of punishment for ‘sins’ of commission or omission (e.g., divine intervention, not working hard enough and not living a ‘healthy’ lifestyle), not dealing adequately with stress and as an opportunity for ‘personal growth’.

These findings support the argument proposed by Taussig (1980, p. 4) that serious illness can plunge the individual into a “vorax of the most fundamental questions concerning life and death”. Serious illness also abruptly interrupts the routine uncritical acceptance of the meaning of life. Conventional understandings are ‘destructured’ as the seriously ill individual queries the basic personal social and moral implications of the illness. Taussig (1980) further suggests that the questions ‘why me?’ and ‘why now?’ signify a crisis in self definition that is created by illness. However, the ‘crisis’ is not the same for individuals living with HIV/AIDS as it is for individuals living with a life-threatening form of cancer. Although this search for reasons to explain the development of their cancer continues for a considerable time individuals are ultimately influenced by interaction with the medical community.

In response to the conflicting information provided to them by members of the medical community individuals begin to understand that even medical science can not always provide answers regarding the cause of cancer. In response to the conflict between beliefs within the common sense and medical discourses creating uncertainty concerning the causes of cancer, the ‘hope’ for cure offered by scientific medicine and the fear of death, individuals with cancer construct subjective meaning for their illness experience. As an integral part of this process these individuals construct self-images as either being lucky, important by making ‘history’ in some form, having a rare form of cancer, providing

assistance to other patients 'following' them, or being provided with the opportunity of achieving personal growth. In contrast, HIV/AIDS informants, who know the medical cause of HIV/AIDS, ask the different self definitional question, 'what now?' In facing the knowledge that their certain death will occur in an uncertain time frame individuals with HIV/AIDS respond in ways which depend on their pre-diagnosis personal perspective. For some individuals living with HIV/AIDS their pre-illness frame of reference is such that it can readily incorporate the experience of diagnosis and its implications without requiring major change. However, for others it appears as though confronting the prospect of their own death destabilises their frame of reference and prompts critical evaluation of their perspective about life and a reappraisal of objects considered to be personally significant.

Parkes (1971) suggested that the self is socially constructed through the individual's 'assumptive world' which, in turn, is created by individuals' from the total set of assumptions developed on the basis of their past experiences. Whenever a major change in state takes place the individual needs to restructure ways of perceiving the world and plans for living in it. Parkes proposed that the expression of grief is dependent on whether the change is construed, by the individual, as a gain or a loss. Irrespective of whether the new situation is perceived as a gain or loss the change is likely to require effort as old patterns of thought are given up and new ones developed (Parkes 1971). The current research extends Parkes' (1971) proposals to clarifying the traditional interpretation of 'why me?' type questions. Diagnosis of a life-threatening illness is not only a major change for individuals that requires restructuring ways of perceiving the world but also it interrupts the routine uncritical acceptance of the meaning of life (Taussig 1980). A function of discourse is to provide structure and understanding of the social and physical worlds. However, where there is uncertainty and conflict within the dominant discourses, individuals struggle to achieve self definition. This struggle to reconceptualise self-images is symbolised by the asking of 'why me?' type questions. Where there is certainty about the cause of illness people ask different types of self definitional questions. 'What now?' questions symbolise individuals asking questions whose answers denote a search for self fulfillment.

In suggesting that 'why me?' type questions signify the individual's crisis of self definition does not invalidate the belief in the expression of anger during this period. People may well express their anger at being confronted with these major changes in their life.

Implications for practitioners

The identification of an experiential discourse has major implications for health care professionals, particularly in relation to counselling, nursing care and medical consultations. These implications arise from a number of issues. Firstly, the fact that this alternative discourse is marginalised by both the common sense and medical discourses means that it is not generally identified by individuals who are not ill. Secondly, individuals living with the illness frequently take on the role of 'carer' and initially discuss their experiences using language and concepts they believe appropriate to the listener's background. That is, they will 'put on a brave face', use humour to discuss their experiences, or refrain from discussing 'negative' emotions or emotive issues such as dying, death, feeling frightened, anxious, overwhelmed, or wanting to give up. Thirdly, in indicating their need to discuss issues in ways other than the dominant discourses, individuals embed symbols indicating their subjective reality. Often these symbols are not easily identified as they are presented in ways that are the antithesis of medical training. That is, they are verbal rather than non-verbal symbols and require aural rather than visual observation skills. Finally, pursuing these embedded symbols requires time, not only to build rapport, but also to allow the individual to divulge these sensitive and vulnerable issues, often in their own timeframe.

Awareness of this marginalised discourse is essential for three reasons. Firstly, it is fundamental for clear, open and unambiguous communication between members of the health care community and patients. Health care professionals need to be aware that patients may make meaning of their illness experience in ways that are different to the meaning the medical discourse attributes to disease (Kleinman 1988). Secondly, in the development and implementation of therapeutic interventions, it is important to understand what is actually occurring to individuals before assessing their responses (Sweeting & Gilhooly 1990). Finally, understanding this experiential discourse enables health care professionals to comprehend that individuals have a range of coping styles and mechanisms that facilitate interaction with the many social objects associated with living with a life-threatening illness. Furthermore, these coping styles may depend on previously developed self-images that have empowered the individual to function effectively in difficult situations.

Accessing this experiential discourse requires two changes from medical professionals. Firstly, to acknowledge its existence and validity as the way individuals actually living with a life-threatening illness organise, categorise and make meaning of their experiences as opposed to attempting to 'educate' individuals concerning appropriate elements of the dominant professional discourse. Secondly, to develop new skills and practices to gain access to this experiential discourse. Primarily health care professionals need to rely less on their problem solving training and develop more specific listening skills. That is, they need to rely less on what they observe (e.g., an individual shedding tears) and, in attempting to solve the problem, making assumptions about the meaning of those tears (e.g., the individual is sad or grieving). They need to develop the sometimes more difficult skills of listen to what is being said, how it is being said, what is not being said and checking out what the individual means in lieu of making assumptions based on a different reality.

It is acknowledged that these changes create a considerable challenge for members of the medical community on two levels. Firstly, it requires them to act in contravention of the political function of the medical discourse. That is, they must suspend their desire to 'educate' individuals concerning the veracity of the medical version of reality and accept the validity of the individual's alternative reality. Secondly, it requires them to go against primary aspects of their professional education. For example, the commitment of often scarce time resources to a task (e.g., actively listening and clarifying individuals' emotional issues) that may be perceived within the medical discourse as diverting them from their primary medical tasks (e.g., cure of disease).

Development of observation and problem solving skills is an important aspect of medical education. These skills are vital in attending to the variety of noticeable changes in a body organ, function or behaviour that may indicate disease or mental or emotional illness. However, disease is a phenomenon that practitioners have been trained to see through the theoretical lenses of their particular form of practice and differs from the illness complaints that patients and family members bring to the practitioner (Kleinman 1988). Diagnostic interviews have a distinct focus (i.e., problem solving), have high amount of interviewer talk-time and use certain interpersonal skills (e.g., more directive) while avoiding others

(e.g., reflection of meaning) (Ivey 1988). These are in conflict with the person-centred task of clarifying subjective meaning and reality.

In relation to grief, a number of accounts of its 'symptomatology' have been developed (e.g., Bowlby 1980; Clayton et al. 1968; Glick et al. 1974; Parkes 1965) and incorporated into the body of medical knowledge. These have been applied to living with a life-threatening illness (e.g., Aldrich 1963, 1974; Rando 1986a) As a component of the professional discourse of grief knowledge about anticipatory grief is entrenched within the medical community (Middleton et al. 1991; Sweeting & Gilhooly 1990) and has been learned as objective reality through the process of professional education (e.g., texts such as Rando 1986b; Schoenberg, Carr, Kutscher, Peretz & Goldberg 1974). When making diagnostic assessments of whether an individual is grieving health care professions frequently refer to lists of commonly accepted grief symptoms (see Stroebe & Stroebe 1987, p. 10). Traditionally, anticipatory grief literature has focused on death as the main object toward which individuals interact (Evans 1994). Furthermore, this literature overwhelmingly supports the belief that in interacting with the knowledge of impending loss individuals begin to grieve in anticipation of the loss. Since few members of the medical community question the validity of anticipatory grief (Middleton et al. 1991; Sweeting & Gilhooly 1990) they observe what they are educated to observe (Siegel & Weinstein 1983) and make diagnostic assessments based on this professionally acquired knowledge. It is taken for granted that crying, in the medical context of being diagnosed with a life threatening illness symbolises that the individual is grieving.

However, the current research has found that contrary to the traditional belief within the anticipatory grief literature, the focus of individuals' imagined futures covers a range of topics. These issues often involve the dreaded issues and events discussed by Bor and Miller (1988). Furthermore, individuals bring into their illness experience a range of self-images that influence the way they interact with their experience of disease and illness as well as how they interact with, and interpret the actions of, members of the medical community. Identifying these important self-images and individuals' fears and anxieties requires development of specific listening skills, the suspension of preconceived ideas and the checking out of assumptions with individuals rather than applying the blanket term

'denial' to individuals who do not respond in ways defined by the dominant medical discourse as 'appropriate'.

Prior to developing and applying psychosocial interventions during the period of anticipating a loss, members of the medical community must first clarify with the individual the focus of the issue. Is the individual focussing on some past loss not related to the current illness (e.g., death of family member, divorce, or change in employment)? Is the individual focussing on some loss related to the illness (e.g., loss of privacy, loss of lifestyle, loss of dependence or loss of body part or function)? Is the individual focussing on some fear or anxiety about the future (e.g., physical deterioration, pain or dementia)? It is then obligatory for the health care professional to clarify what the individual is seeking. In the situation of focussing on the future, the individual may want nothing more from the health care professional than having the depth of their emotional pain or despair or the extent of their fear or anxiety heard and acknowledged. These individuals may merely want quiet comfort and support while they process their fear and anxiety. This request to simply 'be there', without providing advice or trying to 'do something' may be in conflict with the tenets of the medical discourse and medical education. This task also requires health care professionals to recognise their own anxieties and fears, their limitations (temporal, emotional and educational) and, having identified the possibility of emotional issues affecting the patient, making a referral to another appropriate professional (e.g., counsellor or social worker) who has more available time and expertise to explore these issues with the individual.

Health care professionals also need to be aware that interaction with individuals living with a life-threatening illness is a two-way process with each actor 'observing' and 'listening' to the other and then interpreting the other's verbal and non-verbal symbols. The current study found that the most frequent interpretation made by individuals is that health care professionals do not *really* care about the individual. More importantly, they interpret the actions of health care professionals as symbolising they are not able to deal with highly emotive issues such as 'negative' emotions, losing hope, dying, death and being frightened or anxious.

The limitations of the study

There are a number of methodological limitations in the research design and methods employed in the current research. Those relating to the sample characteristics have been referred to in Chapter Four. However, this section further elaborates on these and other related issues. These issues concern the use of cross sectional-design, sample size and sample characteristics.

The use of cross-sectional designs

The main objectives of the current study were to investigate the subjective reality of individuals living with a life-threatening illness, what influences the construction of this reality and what futures do individuals imaginatively construct for themselves. Using a cross-sectional design allows for data collection concerning current events but relies on informants' memory of past events. A long held concern in grief research has been the concern about data that results from selective emphasis of informants' recall. The recall of complex affectively laden events is more likely to be a construction rather than reproduction (Bozeman et al. 1955). In addition, a cross-sectional design does not facilitate the investigation of how fear evolved over time.

The lack of data collected within the two months preceding death limits the generalisability of the current results. It is possible that some of the previously dreaded events or issues may have been resolved in some way, prior to death. Alternatively, the proximity of death may have introduced other dreaded events.

A longitudinal study design would have enabled the collection of data at a number of periods during the process of living with a life-threatening illness and the opportunity to explore the evolution of emotions over time as well as whether the focus of imagined futures changed as individuals perceived their death drawing closer. This type of study design would also facilitated closer examination of individuals life perspectives and whether they remained static or changed over time and under what conditions.

Sample limitations

The composition of the two samples (i.e., the cancer sample predominantly women and the HIV/AIDS sample exclusively homosexual men), their size and self-selected nature affect generalisability of findings.

The sample sizes (i.e., nine individuals living with cancer and nine living with HIV/AIDS) are small. Although it would have been preferable to utilise a more diverse sample, a number of difficulties were experienced in gaining access to a sufficient pool of prospective participants. These difficulties in overcoming the objections of health care professionals who act as gatekeepers in relation individuals with a terminal illness has a long tradition and been raised by a number of researchers (e.g., DeSpelder & Strickland 1983; Family 1992-93; Fulton 1993; Kübler-Ross 1970).

A major aim of the current research was to allow individuals to identify issues they considered important during their experience of living with a life-threatening illness rather than examining researcher imposed issues. Consequently, specific issues such as gender were not intentionally included as a special topic within the interviews. It was originally planned that with similar number of females and males included in the sample, these issues would be identified from the narratives. However, the issues raised in the preceding paragraph made sample selection particularly difficult and precluded inclusion of equal numbers of males and females in the sample. In view of the differences between the two samples concerning the crisis of self definition it is important to repeat the current study with a larger sample of both females and males. It is acknowledged that the gender bias in the current sample precludes generalisations of study conclusions to the general population.

Most studies investigating anticipatory grief have used volunteers. However, few empirical studies have examined the effect of selection bias. The response rate for participation in such studies is generally low. A review of the acceptance rates indicates that approximately half the studies reported response rates of less than 50 per cent (Stroebe & Stroebe 1989-90). The differences between those who volunteer and those who do not volunteer are important. Empirical evidence from the general grief literature has suggested that participants might be coping better than non-participants (Caserta & Lund 1992; Glick et al.

1974; Stroebe & Stroebe 1989-90). This may be because those who volunteers are more prepared to discuss emotional and personal issues than those who decline. Furthermore, they may have significantly different perspectives about the issues associated with their illness experience and different ways of interpreting their subsequent interactions.

The sample in the current research is restricted to individuals diagnosed with either HIV/AIDS or a life-threatening form of cancer. Therefore, conclusions drawn from the current sample related to those individuals included in the research and can not be generalised to the wider community.

Future research agenda

The current research raises a number of issues that warrant further investigation. These are addressed under a number of specific headings.

Definition of illness-related social objects

One of the main reasons for the development of the experiential discourse is that individuals living with a life-threatening illness perceived that they were not 'understood' by non-ill members of the community. This was especially evident during interaction with members of the medical community, particularly medical practitioners, who were perceived as not being interested in the individual's version of events or particular symptoms. This appeared to develop because the same illness-related social objects were given different definitions (e.g., 'symptoms' versus 'side-effects'), and hence different meanings, by individuals and medical personnel. Neither party to this interaction appeared to be aware that the other had a different meaning. Therefore, it is likely to improve satisfaction with these interactions if it is understood how symptoms were defined and what meaning was given to them. An important research project would be investigating what meaning is attributed to which symptoms, under what conditions and by whom.

One method of examining this issue is to prepare brief videotaped scenarios of interactions between various health care professionals and patients discussing a diverse range of issues (e.g., side effects of treatment). Six separate, homogeneous focus groups, each consisting of patients, doctors, nurses, psychologists, social workers and members of the public would view each of the vignettes and be asked to discuss what the group thought were the main

issues for the participants depicted in the video. These focus group discussions would be videotaped and the resultant discussion analysed to identify the social objects discussed and how these were defined by each focus group.

Marginalisation of discourse

Identification of a marginalised experiential discourse raises a number of important questions for members of the lay and medical communities as well as individuals living with a life-threatening illness. Questions relating to the two communities include: Why do both these discourses marginalise the personal experiences of individuals living with a life-threatening illness? Is it merely an issue of healthy others avoiding personal feelings of helplessness and vulnerability experienced when caring for those who are ill as suggested by Siegel and Weinstein (1983)? Do members of the medical community continue to perceive death as the enemy and experience a sense of medical failure or personal mistake when a patient dies (Redding 1986)? How does adherence to these dominant discourses benefit members of each community when interacting with strong emotions? What other issues associated with terminal illness are considered 'unacceptable' by these dominant discourses? What changes need to occur within these discourses to counter these issues?

What aspects of these dominant discourses promotes individuals' acquiescence and inability to challenge their dominance? Does their moral authority reside only in the fact that they are taken by everyone to be beyond dispute as claimed by Miller (1993) or are other factors also present? What political functions of these dominant discourses require change to enable the acknowledgement and validation of the experiential discourse? Finally, how are these issues influenced by social structural features such as gender and medical dominance? Do individuals perceive these as integral aspects of their experience or are they researcher imposed?

Imagined futures

Further investigation is required to identify whether the focus of imagined futures changes as individuals approach closer to death. Do individuals cease fearing dreaded events or issues as they approach death? If so, under what conditions does this occur? Is it because they have 'worked through' these issues to the point where they are no longer held in dread? Is it because other issues become the focus?

Dreaded issues and events

Another area for further investigation is dreaded issues and events. Since these exert considerable influence on how individuals construct their imagined futures it is important to identify their range, their origin, how they develop and how their impact can be lessened. More detailed investigation is necessary to discover what other issues and events are dreaded by individuals facing their own death and what issues are dreaded by significant others. It is likely that in some instances similar issues are dreaded by both the individuals who is dying and the significant other who survives. For example, significant others may also be anxious about or fear the progression of the illness and the individual's consequent physical or mental deterioration. It is also likely that significant others will have different dreaded issues or events. Some people might be generally anxious about how they will cope after the death (e.g., being lonely) or they may fear specific events (e.g., coping with financial matters, coping with routine domestic chores and living alone).

It is also important to investigate whether there is a relationship between previously developed self-images and dreaded events. For example, in the current study one individual dreaded the progression of cancer because she feared that she would not be able to cope. A self-image she had of herself prior to the cancer diagnosis was being 'tough' and 'able to handle anything'. This self-image arose during her childhood experiences growing up with the rough and tumble of two brothers where crying and 'giving in' symbolised being a 'wimp'. Perhaps it was this self-image that inhibited her from seeking a second medical opinion for her initial symptoms.

Self-images

Since the self is considered to be an important concept and influence social interaction, specific investigation is warranted concerning how individuals' self-images influence their interaction with the disease, the illness experience and others, particularly health care professions. Specifically, under what conditions do particular self-images dominate and how does that influence the individual's interpretation of the disease and illness experience? For example, how does the individual's occupation-related self-image influence interaction with health care professionals? Do former health care professionals have experiences that are significantly different to those of their counterparts? Under what conditions does this self-image as a former health care professional influence interaction

during the illness experience? Under what conditions do other self-images 'dominate' the professional self-image? Understanding how self-images influence personal perception of the illness experience will ultimately facilitate a greater understanding of the experiential discourse.

Crisis of self definition

A further question of interest is whether the crisis of self definition occurs across other life-threatening diseases where there is causal uncertainty. For example, do individuals diagnosed with life-threatening heart or kidney conditions experience a similar crisis? Similarly, do individuals diagnosed with longer-term life-threatening illness such as multiple sclerosis and motor neurone disease experience a crisis of self definition? What effect does the slower progression of the disease have on individuals experiences?