

Chapter 1

The Objective, Social and Subjective Reality of Anticipatory Grief

Introduction

The general grief literature suggests that individuals confronted with the expectation that they will encounter a significant loss engage in 'anticipatory grief'. That is, they begin the grieving process in anticipation of that event (Hill, Thompson & Gallagher 1988; Middleton, Moylan, Raphael, Burnett & Martinek 1991; Siegel & Weinstein 1983). Previous research, grounded in the positivist framework, has taken for granted the existence of the phenomenon, despite its limited conceptual and empirical foundation (Siegel & Weinstein 1983). Notwithstanding this general acceptance of the phenomenon there has been no uniformity in operational definitions or the measurements used in its investigation (Fulton & Gottesman 1980; Sweeting & Gilhooly 1990). Siegel and Weinstein (1983, p. 61) suggest that acceptance of the concept is predicated on the widely held assumption that the experience is a positive adaptive response to impending loss "... primarily because it provides a person with an opportunity to rehearse the bereaved role and begin working through the profound changes that typically accompany loss, thereby mitigating the trauma associated with actual bereavement". As a consequence of this belief, health care professionals have advocated the development of interventions during a terminal illness to facilitate 'appropriate' grieving in anticipation of the impending loss (e.g., Walker 1994; Walker, Pomeroy, McNeil & Franklin 1996). However, prior research has been retrospective and focussed on individuals' recall of events and their emotional responses associated with the impending death of a significant other (e.g., partner, child, parent and sibling). In essence, previous research has been based on the implicit assumption that, once informed that death is the probable outcome of an illness, the participants' principal focus is the event of death and its implications.

Although the concept of anticipatory grief has been applied to individuals facing their own death (Aldrich 1963, 1974; Rando 1986a) this has been done in the absence of empirical

work using as research subjects, individuals who are dying (Bergeron & Handley 1992; Hayslip, Luhr & Beyerlein 1991-92). However, the limited conceptualisation of the phenomenon (Siegel & Weinstein 1983) and the accumulation of inconsistent information concerning whether the effects of anticipatory grief on the resolution of grief are benign, adaptive, or emotionally harmful (Rando 1986a), raises two important questions: What is the phenomenon that occurs for individuals when they are confronted with the expectation of a significant loss? And, how do individuals respond to this situation?

Frequently there is a difference between the broader social significance of an event and its reality for the individual. The life-threatening illnesses of cancer and infection with the human immunodeficiency virus (HIV) are no exceptions as they have become a medical syndrome, a socially constructed phenomenon and an individual experience. Social reactions to both diseases are based largely on attitudinal responses to meanings attached to them rather than solely to the conditions themselves (Aggleton & Homans 1988; Holland, Ramazanoglu & Scott 1990; Sontag 1991; Treichler 1992; Viney & Crooks 1992; Watney 1987). Many of the meanings assigned to HIV/AIDS have their foundations in attitudes and values associated with homophobia, marginalised sexuality, racism, (Aggleton & Homans 1988; Gilman 1988; Kamerman 1991; Watney 1987; Weeks 1988) and heterosexism (Holland et al. 1990). Similarly, many of the meanings of cancer are grounded in fears of contagion, degeneration, pain and personal culpability (Sontag 1991). Despite the major advances in treatment for both cancer and HIV/AIDS, which have led to an increased lifespan, and the fact that some people have begun to reconceptualise HIV/AIDS as a 'chronic illness' (e.g., Siegel & Krauss 1991; Treichler 1992), the social construction of both diseases is still predominantly that each is either seriously life-threatening or terminal. Both illnesses also have meaning assigned to them through the social construction of the still largely taboo topic of death (Holland et al. 1990; Stoddard 1989; Treichler 1987; Williamson 1989) and the development of grief theory over the last five decades. Consequently, many health care professionals consider that individuals, with either disease, face grief related psychological issues when confronted with the prospects of an expected death (Kelly & Raphael 1992; Rollard 1990).

Research direction

In contrast to the positivist framework of previous empirical studies, the current study is based on social constructionist theory which posits that reality is constructed through human action and does not exist independently of it. The world, as a meaningful reality, is constructed through human interpretive activity (Berger & Luckmann 1971). The major implication of adopting this approach to investigations in the health field is that health, illness and medical care are viewed as social phenomena: more precisely, as categories constructed by society, or an institution within society, to define and give meaning to certain classes of events (Mishler 1981). Furthermore, a fundamental assumption of symbolic interactionism is that a number of realities exist: an objective reality, a social reality and an individual or subjective reality (Charon 1992). In relation to anticipatory grief, the objective reality refers to what actually occurs to individuals during the period of anticipating a loss, the social reality refers to the social explanation of the objective phenomenon (as per the professional discourse of anticipatory grief), and the subjective reality refers to individuals' construction of their experiences during this period.

The guiding principles supporting the present study were the three major premises of symbolic interactionism. Firstly, human beings act toward social objects within their environment on the basis of the meanings those objects have for them. Secondly, these meanings are acquired from social interaction between and among individuals. Thirdly, these meanings are established and modified through an interpretive process. The significance of using this theoretical framework, in clarifying the concept of anticipatory grief, is that individuals' subjective reality becomes the focus of the study. More precisely, the focus is on how individuals construct their personal experience of illness, what meaning they attribute to it, and what imagined futures they construct. Further questions are raised by adopting this theoretical approach: Is death the primary focus of individuals' thoughts about the future? If not, what objects are the focus of individuals' imagined futures? What meaning do individuals attribute to these objects? And, how do they respond to them?

Another fundamental assumption underpinning the study is that individuals' reactions to imagined future scenarios do not occur in isolation but as an integral part of the ongoing experience of living with a life-threatening illness. How individuals respond to their

imagined future is grounded in their interaction with, and interpretation of, other aspects of the illness experience. In turn, this subjective illness experience is grounded in social interaction with other members of the community and the individual's interpretation of this ongoing interaction. Also, the development of a life-threatening disease does not occur in isolation but within the rich context of social interaction, during routine daily life. Forming the foundation for these beliefs is acceptance that the relationship between human beings as producers, and the social world, their product, is and remains a dialectic one. That is, individuals and the social world interact with each other: The product acts back on the producer (Berger & Luckmann 1971). Furthermore, individuals' selection of a particular line of behaviour in any interaction involves a complex symbolic process in which they make a number of evaluations. These include evaluating (a) the demands of others immediately present, (b) the self-images individuals develop through role taking, not only with those in the current situation but also with others not actually present, (c) the normative expectations they perceive exist in the situation, and (d) the disposition to act toward any other objects the individual may interpolate symbolically in to the interaction (Charon 1992). Therefore, examination of how individuals construct their subjective experience of illness must include investigation of individuals' interpretation of how the wider community, and any specific specialist group, such as the medical profession, defines, categorises and makes meaning of the relevant experiences associated with living with a life-threatening illness.

Study aims

This thesis is a sociological analysis of the influence of discourses on the subjective experience of living with a life-threatening illness. The current study sets out to clarify the concept of anticipatory grief by using the theoretical framework of symbolic interactionism to address the following questions:

1. What is the subjective reality for individuals living with a life-threatening illness?
2. What influences the construction of this reality?
3. What future do individuals living with a life-threatening disease imaginatively construct for themselves?
4. How do they respond to their thoughts of these imagined futures?
5. How does this perspective differ from the common sense and medical discourses?

In essence, the current study examines how individuals interpret the perspectives of the common sense and medical discourses of cancer and HIV/AIDS and how specific elements of these perspectives influence individuals' early experience of a life-threatening illness. It focuses on identifying how individuals living with cancer and HIV/AIDS symbolically designate particular social objects associated with their illness experiences and how they interact with these objects. It does not attempt to provide a comprehensive catalogue of all known elements of these discourses or identify how these elements originated.

Central propositions

The following propositions are central to the current investigation.

Proposition One

The concept of anticipatory grief does not accurately reflect the actual experiences of individuals living with a life-threatening illness.

Proposition Two

Within Australian society, the way of structuring the social world of life-threatening disease and illness is dominated by two overlapping, and equally valid perspectives: that of the general community (the common sense discourse) and that of the medical community (the medical discourse).

Proposition Three

As a description of reality that 'goes without saying' the common sense discourses of cancer and HIV/AIDS constitute a form of reality that is taken for granted by non-medical members of the community. These individuals accept, and internalise, this form of reality as consisting of objective truths outside human intervention. Consequently, individuals' initial responses to their diagnosis of cancer or HIV/AIDS are influenced by particular elements of the relevant common sense discourses.

Proposition Four

As individuals proceed through their illness experience they engage in social interaction with members of the medical profession and are introduced to ways of defining, classifying and categorising social objects, associated with each disease, that differ from those used

within the common sense discourse. Developing a subjective meaning and reality of their illness experience challenges individuals to resolve the differences between the ways of defining and categorising these social objects.

Proposition Five

Individuals living with a diagnosis of either cancer or HIV/AIDS perceive that their illness experience is not always accurately reflected by either of the 'dominant' discourses. Through social interaction with other people who are also living with these illnesses individuals develop a shared understanding of, and way of structuring, their illness experience. They also perceive that although this 'experiential discourse' validates their personal experiences, it is marginalised by adherents of the dominant discourses.

Proposition Six

Individuals living with a life-threatening illness use previously developed self-images in the imaginative construction of their future. The focus of these imagined futures varies depending on the importance given to any one of a number of different social objects.

Proposition Seven

Differences in knowledge about each disease, their outcome, incidence within the wider community and stigma result in different social objects being given priority as the focus in each illness experience. As a result illness experiences between cancer and HIV/AIDS will differ in some aspects.

Overview of chapters

Chapter Two outlines the prevailing background attitudes to dying and death, the increasing influence of medicine on social issues, the social institution of health care, the transmission of specialist health care knowledge, social control, and the medicalisation of social 'problems', particularly grief. The idea that medical knowledge is socially constructed is introduced and sets the tone for an examination of the literature relating to the development of the concept of anticipatory grief.

The theoretical underpinning of the current study is presented in Chapter Three. The main concepts of symbolic interactionism are introduced. This is followed by a discussion of the

importance of language and discursive processes and practices in the ordering of perceptions, the determining of subjectivity, the construction of social interaction and the making of diverse social and physical worlds meaningful for social actors. The concept of discourse, as a way of coherently describing the physical and social worlds, is introduced and the distinctions between common sense and professional discourse is made and related to the current research problem. The concept of health, as it is used in the construction of self and the unhealthy 'other', is discussed along with its impact on interrupting social relations. The chapter concludes with a discussion of how individuals symbolically designate elements of the medical discourse and then act toward those objects.

Chapter Four outlines the research design and methods for the current study. It includes discussion of the rationale for selecting the diseases of cancer and HIV/AIDS, issues influencing the evolution of the current study, the sample size and composition, limitations to the study arising from the sample and how data analysis was conducted.

Chapter Five identifies a number of elements of the common sense discourses about cancer that create dilemmas for informants in the current research. This chapter also provides a descriptive analysis of how these elements influence individuals in two ways. Firstly, it describes individuals' initial interaction with the personally unfamiliar social objects associated with living with life-threatening forms of cancer. Secondly, it describes how these elements also influence individuals' reconceptualisation of self-images.

The aggressive treatment processes for cancer exposes individuals to a range of elements of the medical discourse of cancer. In turn, these discourse elements become objects which individuals symbolically designate and then act towards. Chapter Six identifies the most important of these elements and the patients' subsequent construction of the medical discourse. Particular emphasis is given to the objectified elements of the medical discourse that created dilemmas for individuals in the current research project in that they conflicted with their personal illness experience or self-image.

During the early experience of diagnosis and treatment of a life-threatening form of cancer individuals respond in ways defined by dominant discourses. However, as they progress

through the illness experience individuals become aware that some of their personal issues and experiences are not in common with either beliefs within the common sense discourse or their perception of the medical discourse. How individuals deal with the dissonance created by the difference between their personal illness experience and the dominant discourses and how they construct their own 'experiential discourse' is discussed in Chapter Seven.

Chapters Eight and Nine focus on the disease of HIV/AIDS. A number of specific elements of the common sense discourse of HIV/AIDS create dilemmas for individuals living with the infection. Chapter Eight is a descriptive analysis of individuals' interaction with these elements, particularly the effect this interaction has on their self-image. The chapter also discusses how in responding to the concept of the unhealthy 'other', individuals engage in activities to distance themselves from the effects of the common sense discourse.

Chapter Nine discusses how these individuals interact with others and whether non-infected members of the community respond to issues of morality or mortality. The influence of individuals' pre-illness frames of reference on living with the disease is discussed prior to an examination of what triggers individuals' thoughts of the future, the social objects that form the focus of these thoughts and individuals' responses.

The final chapter draws together the conclusions arising from the current study, discusses their limitations and provides recommendations for clinical practices within the medical community and further research.

Chapter 2

Critical Review of the Literature

Attitudes to dying and death

Throughout the ages social institutions have played an important role in shaping community and individual responses to dying and death. They have done so by providing meaning for living, explanations for mortality, opportunities for personally transcending death and shielding people from the anomic terrors of death (Kearl 1989). Some of these powerful social institutions influenced the death fears of society by employing their fears as mechanisms of social control or through being the actual causes of death (Kearl 1989). The political and military influence in the social construction of death has been outlined by Umberson and Henderson (1992). However, demographic, institutional, and attitudinal changes concerning dying and death have been considerable over the past one hundred years (Pine 1986). As demonstrated by Mitford (1980), and reflected in literary works such as Waugh's *The loved one* (1951), social aversion to both dying and death has emerged (Corr 1993; Kastenbaum 1993; Kastenbaum & Costa 1977; Kübler-Ross 1970; Usher 1991), particularly as they became less integrated at the familial level and less common as an everyday experience (DeSpelder & Strickland 1983; Pine 1986). Other social changes such as variations in life expectancy and mortality rates, increased geographic mobility of families, changing causes of death, the advent of life-extending technologies, the displacement of death from the home to an institutionalised environment, and changes in the practice of medicine also influenced individual and community responses to dying and death (DeSpelder & Strickland 1983; Fulton 1989b; Kearl 1989; Sudnow 1981).

Religion is recognised as having been the traditional social institution that provided the cultural explanations for the occurrence of death, the ritual and hope for members of the community who were facing their death (Aries 1981; Kearl 1989) and the management of losses, particularly those associated with death (Macnab 1989). This religious influence extended from spiritual explanations of death and how individuals should prepare themselves for the event, to post-death rites and ceremonies and the physical control of places of burial. For example, for the first thirty years of white settlement in Australia, not

only was the Anglican Church the only authorised agent to conduct funerals but they also had control of cemeteries (Griffin & Tobin 1982). However, the religious monopoly over death was broken with the rise of secularisation and the pervasive effect of the scientific perspective within society. The church was replaced by other powerful social institutions as the major influencing agent on attitudes toward dying and death (Kearl 1989). In Western societies the physician took over from the priest as the most appropriate guardian of society and the individual (Crawford 1984; Rosenberg 1988). With movement into preventative medicine it is now the medical establishment that has become the major social force in organising much of contemporary life. Health education, with its widespread use of the term 'lifestyle', offers a new way of thinking about health as a personal choice, a social status, as something chosen according to rational health criteria, a plan and a pattern of consumption demonstrating personal responsibility (Crawford 1984; Hetzel & McMichael 1987). The community is constantly bombarded with health related advertising campaigns that encourage its members to embark on healthier lifestyles and eat certain foods to avoid future health problems such as heart disease, diabetes, cancer, and lung problems.

The shift in social influence over death, from religion to medicine, and the profound changes in medical practice have also impacted on the psychologies of individuals. Whereas under the influence of religion premature death was seen as generating moral doubt (Aries 1981), the ascendancy of the social institution of medicine has generated the belief that premature death is now avoidable, being caused either by an inadequate lifestyle, for example smoking, poor diet, lack of exercise, or, in the case of HIV/AIDS, an individual's sexual preference (Crawford 1994; Kearl 1989).

The social institution of health care

The social institution of health care consists of various health professions whose work is organised around the traditional, specialist activities of medicine, namely, the preservation and restoration of health (Averill & Nunley 1988), through the diagnosis, care, and treatment of disease, and is dominated by doctors as a particular profession (Mishler 1981; Willis 1989). It is acknowledged that each of the individual professions within this wider health care group has its own individual identity and could be examined in isolation. Also, it could be argued that each specific health care profession has its own objective reality and that the subjective reality of some members will differ from the general objective reality of

the individual profession or that of the wider social institution of health carers. For example, some health care professionals, (e.g., Peterson, Beck & Rowell 1992; Whelan & Warren 1980) believe that individuals with a terminal illness proceed sequentially through the stages of dying proposed by Kübler-Ross (1970). This view is definitely not held by all health care professionals (Attig 1991, 1991-92; Corr 1993; Worden 1983). In turn, this difference in reality will influence flow of knowledge both within and from the group, a situation eloquently outlined by Kübler-Ross (1970) in relation to dying and death. However, in the context of this thesis it is more relevant to examine these professions as a collectivity: the social institution of health care. Investigation will centre on certain aspects of scientific medicine, namely, the specific body of knowledge associated with the provision of health care to individuals living with a life-threatening illness.

The Australian context

In the Australian context the production of health services is based on a complex arrangement of a socially organised structure known as the division of labour (Davis & George 1993; Willis 1989) which has two main features. It has an hierarchical nature and is dominated at three levels by the medical profession: medical autonomy over their own work as professionals; medical authority over the work of other health occupations; medical sovereignty, referring to the dominance of the medical profession in relations between the institution of health care and the wider society (Willis 1989). It is medical sovereignty which is of interest in this thesis.

Doctors are perceived as institutionalised experts on all matters relating to health (Willis 1989) and possessing the power to label illness as a deviation from the biological normality and thus one of 'abnormality' (Davis & George 1993). Furthermore, they form part of a 'community' of health carers that is supported by its own body of images, allegories, and meanings, its own language, specialised roles, maxims, beliefs, and mythology. These features, which developed in response to the institution of health carers' particular specialisation, structure routine interpretations and conduct within the institutional area. That is, within the institution of health care has developed a discourse that is a coherent system of describing and categorising the physical and social worlds of medicine. This reality is also legitimised by the status of the body of health care knowledge within the wider social reality (Comaroff 1982). Both members of the health care community and

members of the wider community acknowledge the existence of this specialised body of knowledge. The roles associated with the health care community are sanctioned by both the general society and the social institution of health care (Berger & Luckmann 1971). So too are the roles of those outside the health care community, that is, patients, who seek these specialised health care services (Noyes & Clancy 1977; Parsons 1951).

In contrast to the 'base-world' of the general society, acquired in primary socialisation, the institution of health care is a 'sub-world', or partial reality internalised through both primary and secondary socialisation. Institutionally defined membership of this sub-world, which does not result in exclusion from the wider base-world, is dependent on being a carrier of the special knowledge of the particular sub-world. However, a sub-world can also be perceived as a socially constructed, cohesive reality characterised by normative, affective, and cognitive components (Berger & Luckmann 1971; Holland et al. 1990). Professionals within the social institution of health care have claimed that their activities and knowledge are not simply specialised segments of information available to all members of the community, but they possess a special technical status which sets them apart from everyday life (Mishler 1981).

As in the wider society, the social institution of health care has its own socially defined objective reality including 'rules and regulations' governing its roles, structures concerning knowledge transmission and retention to whom such information will be disclosed and from whom it will be withheld. This is particularly relevant to knowledge regarding a life-threatening illness. For example, it is frequently members of the medical profession who decide what information should be relayed to patients. Many doctors are still reluctant to speak of death with a dying patient and family despite the current arguments which favour such frankness (Cochrane, Levy, Fryer & Oglesby 1991-91; Family 1992-93; Fulton 1989b). In addition, some of the knowledge of this sub-world is considered relevant to all members of the institution, while other segments of the same knowledge are considered relevant only to certain members of the specialised group. The reality of who is considered relevant to have access to all of this specialist knowledge and what knowledge is transmitted, by whom and to whom, is socially defined by the specialist institution (Berger & Luckmann 1971). For example, the institution of medicine defines what information specialist oncologists will disclose to a patient's general practitioner and also what

information may only be disclosed to patients by the medical profession and what may be disclosed by nursing staff.

Transmission of specialist health care knowledge

Within the institution of health care, knowledge is transmitted to new members of the group through the secondary socialisation process which includes internalisation of role-specific language, socially defined roles and the undertaking of specialised 'professional' education (Berger & Luckmann 1971). Through socialisation, predominantly the secondary socialisation of professional education, the special knowledge relating to the health care institution is learned as objective 'truth'. This objective truth is internalised as subjective reality which, in turn, has the power to shape the individual. This reality produces a specific type of person, namely a health care professional, whose identity and biography as a health care professional have meaning only in a society that has produced this particular knowledge to define and control the social world (Berger & Luckmann 1971).

In relation to dying and death, members of the institution of health care are influenced by the socialising effects of wider community changes as well as the specific changes associated with professional education. Since fewer deaths now occur within the family environment, fewer members of the community have personal experiences of death prior to reaching middle adulthood (Kastenbaum 1993). Until the advent of HIV/AIDS, death was becoming a stranger to the younger members of the community. These community changes have a significant effect on those individuals entering the institution of health care. Not only do these trainees have to cope with an institution that emphasises its curative aspect, but also few trainee doctors and nurses, for example, have had to face death as a significant part of their personal life experience (Kastenbaum 1993; Lewis 1979). This lack of significant experience with dying or death has ramifications for trainees, as well as trained professionals, interacting with dying patients (Usher 1991). Confronted with death, perhaps for the first time in their lives, trainee health care professionals are likely to experience strong emotions within themselves. Without the benefit of prior experience, individuals are likely to engage in a range of behaviours that enable them to maintain a perception of themselves as functioning as efficient members of the health care team. Some health care professionals discount the patient's or family member's feelings (McKissock 1978). Others engage in physical withdrawal from the patient or family (Bowers, Jackson, Knight & Le

Shan 1964; Caty, Downe-Wamboldt & Tamlyn 1982; Holman 1990; Kübler-Ross 1970; Schults & Ademan 1976). Engaging in medical heroics, such as the resuscitation of a patient experiencing myocardial infarction despite a pre-existing terminal illness which is likely to cause the patient's death within a matter of days, are also ways health care professionals respond to emotional issues associated with dying (Coombs & Powers 1975; Konner 1993; Macguire 1985).

The student in any of the health care professions who learns about the care of the patient with a life-threatening illness also is likely to learn the basic values of scientific medicine where a high priority is attached to life. Frequently, emphasis given to the life saving technological aspects of scientific medicine during professional education, and subsequent practice of the health care professions, is at the expense of the emotional well-being of the patient, family, and ultimately the health care staff (DeSpelder & Strickland 1983; Usher 1991). It has been suggested that in health care training:

... death has become the enemy; and in losing a patient, doctors often feel that they have failed medically, or worse still, made some terrible mistake. (Redding 1986, p. 372)

Edwardson (1985, p. 84) reports evidence to support this position particularly when "... the overriding focus of the therapist is cure or control of disease". Frequently, for the health care professionals, the idea that the death of a patient represented a failure was not verbalised but subtly perpetuated and rarely was dying or the events surrounding death viewed as a potentially appropriate part of life (Barton 1972; DeSpelder & Strickland 1983; Kastenbaum 1993; Sudnow 1981). This attitude has serious implications for the way in which the members of the institution of health care provide their services to those members of the community who have a life-threatening illness or who may be terminally ill. Without the knowledge and skills to deal with their own emotional conflicts around death, the health care professional is often unable to provide adequate support for, or even understand the nonmedical needs of dying individuals or their families. For example, the health care professional who relates to a dying patient in a cold, detached manner or by severing a relationship, may be compensating for underlying feelings that are painful to acknowledge (DeSpelder & Strickland 1983; Kübler-Ross 1970). Notwithstanding these deficiencies, the medical professional, as a pivotal figure in our society's death system, exerts much

influence over the general climate of thought and feelings, and also over other members in the system.

Wright and Treacher (1982) suggest that until recently medical knowledge remained behind an unbreachable conceptual barrier. One of the reasons for this situation was a fundamental assumption that the foundations of medical knowledge were firmly grounded in the findings of modern science. Furthermore, it was held that the precepts of science were incontrovertible. However, medical knowledge is inseparable from social relationships and social experience and can be viewed as a social construction (Mishler, AmaraSigham, Osherson, Hauser, Waxler & Liem 1981; Wright & Treacher 1982).

Social control

It has been argued that departure from the institutional order is interpreted as individual dysfunction that requires therapeutic intervention to ensure a return to the institution's socially constructed, and 'true', reality (Berger & Luckmann 1971). One conceptual mechanism for institutions to maintain their objective reality, and ensure that actual or potential 'deviants' remain within the institutionalised definitions of reality, is the development of a body of knowledge that includes a theory of deviance, a diagnostic apparatus, and a conceptual system for the cure of 'lost souls' (Berger & Luckmann 1971). Various designations are applied to such deviant behaviour. For example, homosexuality, considered a radical departure from the 'normal' sexual orientation of the majority in society was labelled a 'mental illness' by the medical establishment prior to 1973 (Isay 1989; Sarason & Sarason 1987). As a deviation from the religious institutional order homosexuality has been seen regularly as 'moral depravity'. Altman (1992a) argues that the HIV epidemic has contributed to a greater recognition and legitimacy for homosexuality in Australian society but the shifts in discourse have not been all in the same direction. These movements range from the insistence of the moral right that permissiveness is inherently wicked and leads to divine punishment through to publications produced by various community-based organisations which extol 'safe sex' as a means of expanding sexual adventures (Altman 1992a).

In Australian society in the 1990s homosexuality is given different meanings by different social institutions. For the gay community specifically, and some members of the general

community and even some members of religious institutions, it is considered one variation on the continuum of human sexual responses; other members of religious institutions and the wider community continue to see homosexuality as moral depravity.

Medicalisation of social problems

It has been argued that medicine, like the social institutions of religion and law, is a moral enterprise that seeks to uncover and control things that it considers undesirable (Kearl 1989; Mishler 1981). Simultaneously, Western societies are increasingly expecting the medical professions to deal with intractable social problems that resist conventional means of social control, redefining them as illnesses that fall within the control of a medical regime (Davis & George 1993). This medicalisation of socially undesirable problems has seen the evolution of alcoholics from drunkards, victims of various learning disorders from previously poorly performing students, and the individual with senile dementia from the elderly citizen disoriented by dramatic social change.

Dying and death have not escaped this medicalisation process which, together with its use of increasingly more sophisticated technology and drug therapies, has engendered a community belief that medical science will provide a cure for whatever ails them and thus ensure immortality (Kearl 1989). The increasing number of victories over previously death-causing diseases has led to a widely held belief that it is simply a matter of time before death is defeated completely (Kastenbaum & Ainsberg 1972; Kearl 1989). Recent developments in cryogenics, with its belief that future medical science will be able to successfully thaw the body, treat the death-causing disease and reinstate the individual to former life and health, demonstrate that many people support this belief (DeSpelder & Strickland, 1983).

The medicalisation of grief

The reason why the health care professions began to see dying and death as a problem around the mid-1950s is open to conjecture but the emerging humanitarianism surrounding the problems inherent in all types of infirmities, illnesses and disabilities appears to have been influential in the increased concern for adequate social human services, including psychiatric and social work care of dying people and their families (Kastenbaum & Costa 1977; Pine 1986).

The extensive literature available on grief predominantly consists of accounts of the response to the death of a close family member (Fowlkes 1991) and reflects the influence of the institution of health care. Perusal of this literature reveals that the most common understanding of grief is as a private emotional experience with a predictable symptomatology. Grief is viewed substantially in terms of the intrapsychic attributes of the individual in conjunction with the effects of the timing and cause of death and certain demographic variables (Fowlkes 1990). Frequently grief is viewed, both in serious scholarly work and popular discourses, as if it were a non-fatal disease. Contained within the assumption that grief has a normal course, or a set of expected symptoms which progress in a generally predictable manner, is a belief in its biological grounding (Lofland 1985). This situation continues despite the identification of a number of empirically unsubstantiated assumptions existing within the general grief literature (Wortman & Silver 1989). As with the medicalisation of other social problems, by utilising the biomedical model to construct and give meaning to grief (Macnab 1989) the institution of health care established further control over the general community. This has occurred despite the lack of clarity and precision of commonly accepted definitions of grief and related concepts (Caroff & Dobrof 1975; Middleton et al. 1991; Rodgers & Cowles 1991).

Lindemann (1944-45, p. 141), an American psychiatrist, was the first to identify grief as a "... definite syndrome with psychological and somatic symptomatology". His article, along with Freud's *Mourning and melancholia*, first published in 1917, has been elevated to the position of 'classic' (Stroebe & Stroebe 1987; Worden 1983) which has often meant that their conclusions are accepted as though they were established fact rather than being subjected to critical evaluation (Shackleton 1984). In the field of bereavement, for instance, papers are regularly introduced with reference to Freud's concepts of grief, depression, and mourning. In conceptualising bereavement there is also the inevitable reference to Lindemann's pioneering work with "... 101 relatives of people killed either in Boston's Coconut Grove fire or in war" (Raphael & Middleton 1987, p. 6). This situation continued despite the fact that Lindemann's work would not satisfy current methodological standards (Stroebe & Stroebe 1987).

Minimal academic debate has been devoted to either Lindemann's methodology or conclusions or the fact that in Freud's paper it was clinical depression that was at the centre

of interest rather than the psychological process of grief itself (Stroebe & Stroebe 1987).

Many authors citing Lindemann's work (e.g., Kalish 1985; Rando 1984; Worden 1983) often make the same error as Raphael and Middleton (1987) by implying that his sample was dominated by survivors of the Coconut Grove fire or family members of service personnel killed in combat. In fact, Lindemann (1944-45) fails to provide adequate information concerning the distribution of his sample of '101 patients' apart from the following four categories:

1. psychoneurotic patients who lost a relative during the course of treatment;
2. relatives of patients who died in the hospital;
3. bereaved disaster victims (Coconut Grove fire) and their close relatives; and,
4. relatives of members of the armed forces.

It is only later in the paper that Lindemann indicates that there were "... 13 Coconut Grove fire victims" (p. 144), a figure that conflicts with information contained in a previous, rarely cited article co-authored with Cobb (1943).

In discussing their observations of some neuropsychiatric abnormalities occurring on the disaster ward of the Massachusetts General Hospital, particularly in response to the Coconut Grove nightclub fire, Cobb and Lindemann (1943, p. 823) stated that "... of 39 patients admitted to the hospital, seven died within 62 hours. Of the survivors, at least 14 presented neuropsychiatric problems". Clearly the sample used by Cobb and Lindemann consisted of individuals who had sustained physical injuries, during a major fire, that necessitated hospitalisation for more than eight days, as well as had experienced the death of a close family member during the disaster. The situation described by Cobb and Lindemann (1943) does not reflect normal circumstances surrounding the death of a family member. In fact, the experience of these individuals is more aligned to Post-Traumatic Stress Disorder as described by Fowlkes (1990). Furthermore, "... seven patients became problems of psychiatric study and management because their recovery was complicated by severe grief" (Cobb & Lindemann 1943, p. 318).

Although all seven patients "... showed considerable variation in their reactions" Cobb and Lindemann (1943, p. 819) identified the following syndrome that was common to all of them:

... sensations of somatic distress occurring in waves lasting from 20 minutes to one hour; a feeling of tightness in the throat, choking with shortness of breath, need for sighing, and an empty feeling in the abdomen, lack of power in the muscles, and an intense subjective distress described as tension, lonesomeness, or mental pain. The patient soon learned that these waves of discomfort could be precipitated by visits, by mentioning the deceased, and by receiving sympathy. There was a tendency to avoid the syndrome at any cost, to refuse visits lest they would precipitate the reaction, and to keep deliberately from one's thoughts all references to the deceased.

Having described these patients as experiencing 'severe grief' that complicated their recovery, Lindemann (1944-45) used the same description, almost word for word, to identify the symptomatology of normal grief. In effect, what was described in the initial paper (Cobb & Lindemann 1943) as severe grief, was described as normal grief in the later paper (Lindemann 1944-45).

Apart from the problems associated with applying the same description to contrary conditions, and the lack of normality of their sample (Clayton, Desmarais & Winokur 1968; Clayton, Halikas & Maurice 1971), serious doubt must be raised concerning the conclusions reached by Cobb and Lindemann (1943) due to the conflicting information concerning their sample size and composition. Initially, the psychiatrists were invited to review all patients still on the ward eight days after the disaster and they stated "... seventeen patients have been so reviewed" (p. 815). Later in the article, when discussing reactions to bereavement the sample size is given as "seven" (p. 818), while in their discussion section Cobb and Lindemann claim "... of 39 patients admitted to the hospital, seven died within 62 hours. Of the survivors, at least 14 presented with neuropsychiatric problems" (p. 823). When read in conjunction with Lindemann's 1944 article that refers to "... the 13 Coconut grove fire victims" (p. 114), the reader is left wondering precisely what conclusions were drawn from which sample. Despite these glaring inconsistencies, which have not been the subject of later scrutiny and debate, Lindemann's 1944 paper is still revered as a classic and still forms the foundation for the majority of later work in the grief literature.

The social construction of medical knowledge

The biomedical model is based on the following fundamental assumptions. Firstly, disease is defined as deviance from normal biological functioning. Secondly, it encompasses the doctrine of specific aetiology. Thirdly, it incorporates the universality of a disease taxonomy. Finally, the scientific neutrality of medicine (Mishler 1981). These underlying assumptions influence both the practice of medicine, and health care generally, and the development of scientific medicine. In addition, the linguistic basis of biomedical knowledge influences the way in which scientific medicine objectifies reality within the institution of health care. As a set of categories used to both filter and construct experience, modern scientific medicine predisposes health care professionals, individuals, and the community to notice certain features of life and to describe them with a special vocabulary (Wright & Treacher 1982). Terms such as 'shock', 'stress', 'premenstrual tension', and 'depression' both organise and colour individuals' experiences of themselves. The biomedical model also influences the ways individuals with illnesses are perceived. Furthermore, how ill individuals are apprehended structures their treatment, status, their self understanding, and their response to the complex interaction of social and biological forces that are labelled disease (Gilman 1988; Taussig 1980). As the following review of the literature will demonstrate, this dominant framework for research has influenced the classification and development of the concept of anticipatory grief.

Social constructionist theory posits that reality is constructed through human action and does not exist independently of it; the world, as a meaningful reality, is constructed through human interpretive activity. Although there are a number of implications concerning this approach to investigations in the health field (see Lupton 1994a; Mishler et al. 1981) the most relevant implication for this thesis is that health, illness and medical care can be viewed as social phenomena: as categories constructed by society, or an institution within society, to define and give meaning to certain classes of events (Mishler 1981). Culturally specific values, norms, and shared rules of interpretation dictate whether or not a particular experience or behaviour, within the health field, is viewed by members of a society as a sign or symptom of illness. Although the same biological processes associated with disease might be observed in different cultures the specification of behaviours as signs of illness will be given different meanings. Within Western societies the distinction between signs

and their meaning as disease is, in part, a difference between health professionals' definition of patient problems and the actual experience of patients (Mishler 1981).

Social constructionist theory also proposes that reactions to specific events follow from people's ideas or concepts held about those events and from interpretations placed on them. From this assumption it can be argued that particular 'social constructions' originate when an unprecedented event occurs and meanings are attached to it on the basis of ideas, beliefs, knowledge and experience associated with similar events, or ideas constructed about the new event. For example, using the concept of the 'Good Death' Kellehear (1990) traced the development of the moral and social ideas for dying behaviour. In examining the social interactions between the individual who is aware that he or she is dying and the central social institutions of the wider society, Kellehear identified socially defined sets of expectations and exchanges that individuals feel obliged to fulfil. Common features in the overall social experience of dying include:

1. the individual developing an awareness of their own dying;
2. engaging in social adjustments and personal preparations involving intimate relationships;
3. undertaking public preparation in the form of finalising wills and funeral arrangements;
4. relinquishing formal work duties, and,
5. responsibilities and making formal or informal farewells to friends and family.

Kellehear and Fook (1991) also suggested that it is a commonly held professional and community view that individuals' failure to engage in 'proper' preparation for their death suggested denying, careless or maladaptive behaviour. Rather than indicating psychological maladjustment, individual differences in dying behaviour might be understandable partly, at least, in terms of social reasons (Kellehear & Fook 1991).

The following review of the literature demonstrates that when first 'discovered' the concept of anticipatory grief was given meaning based on beliefs, knowledge and experience associated with the reaction to traumatic death rather than actually questioning what was occurring for individuals or how individuals interpreted their experience. It also illustrates how development of the concept has been influenced by the process of social

construction which, in turn, led to conceptual confusion and the problematic development of the concept.

Development of the discourse of anticipatory grief

Introduction of the concept

The concept of anticipatory grief was introduced by Lindemann (1944-45) in an apparently independent study of individuals' responses to routine death. However, there were common elements between this sample and a sample from a previous study. The initial work was conducted on a group of people recovering from personal injuries received during the Coconut Grove nightclub disaster. Although it is not clear precisely who was included, some of the survivors of the disaster formed a part of the sample for later work on identifying normal grief.

The original work undertaken by Cobb and Lindemann (1943) was in response to requests for psychiatric assistance with survivors of the Coconut Grove nightclub fire. Its focus was on individuals' emotional adjustment to the disaster and all its implications, namely, "... disfigurement, lasting disability, loss of work, bereavement, and disturbed social situations" (Cobb & Lindemann 1943, p. 814). The services of clinicians (Cobb & Lindemann) were sought when the response of some family members to the discovery of a body had attained "... the proportions of a major psychiatric condition and needed trained intervention" (Cobb & Lindemann 1943, p. 814). All the victims reported in the article experienced both personal injuries during the fire and the death of a close family member, or significant friend, in the disaster. In some cases the survivors were not informed of the death of significant others until several days after the fire. However, despite these physical and emotional injuries, the fact that at least fourteen presented with "... neuropsychiatric problems" (p. 823) and the recovery of seven people was complicated by severe grief, it was claimed that a distinct syndrome, common to all, was identified. This was categorised as an acute grief reaction (Cobb & Lindemann 1943). Notwithstanding the identification of this grief reaction, the article was not primarily about grief *per se* but some of the neuropsychiatric abnormalities which occurred in a 'disaster ward'. The article's conclusions were concerned with identifying the psychiatrist's role as a member of a disaster team. The activities reported in the article were based on anecdotal evidence

collected during practical experience on the disaster ward of a hospital. This experience was to influence later work on family members' responses to routine death.

In a second study, Lindemann (1944-45) combined the Coconut Grove disaster sample with three other groups, namely psychoneurotic patients who lost a relative during the course of treatment, relatives of patients who died in the hospital, and relatives of members of the armed forces. The implication in this later article (Lindemann 1944-45) was that this composite group formed the basis of an independent study. No mention was made of the original psychiatric referrals of the Coconut Grove component of the second sample or whether members of the other groups were referred for prior psychiatric conditions. These four groups were presented simply as experiencing normal grief or its variations.

In essence, the purpose of the second article was to define and make meaning of people's reactions to the death of a close family member. The focus was on the reactions to death rather than the circumstances in which it occurred. It was implied that all those involved in this study on normal grief were responding to a routine death. The brief outline of the methodology stated that the investigation was based on a series of psychiatric interviews. These interviews were subsequently analysed and the psychiatrist "...avoided all suggestions and interpretations until the picture of symptomatology and spontaneous reaction tendencies of the patients had become clear from the records" (Lindemann 1944-45, p. 141). However, the influence of the original study on the second piece of research is clearly evident in the form of the description of the symptomatology of the normal grief syndrome. Apart from minor changes in tense and word placement the descriptions are identical. Furthermore, in the original article a case history was used to illustrate the point that a psychotic episode after the disaster could be traced to a previous history of maladjustment in times of stress. In the second article, however, this same case history was used to represent "agitated depression" (p. 146) — a distortion of normal grief in response to a routine death. Yet no reference was made to the person's history of maladjustment in times of stress.

It was with this focus on death in the main body of the article that attention was turned, in the final paragraph, to making meaning of returning soldiers' experiences. Several instances were reported where soldiers returned from the battle front to find that their wives

no longer loved them and demanded an immediate divorce (Lindemann, 1944). This was the unprecedented event that required explanation. Based on previous knowledge and ideas about separation through actual death, Lindemann attempted to make meaning of this new event. It was proposed that the desire for divorce was the direct result of the threat of death during wartime separation. Lindemann (1944-45, p. 147) concluded that:

The patient is so concerned with her adjustment after the *potential* death of father or son that she goes through all the phases of grief - depression, heightened preoccupation with the departed, a review of all the forms of death which might befall him, and anticipation of the modes of adjustment which might be necessitated by it. [Emphasis added]

Continuing the emphasis on death, it was further concluded that “While this reaction may well form a safeguard against the impact of a sudden death notice, it can turn out to be of a disadvantage at the occasion of reunion” (Lindemann 1944-45, p. 148). It was argued that, in the face of an anticipated death, “... apparently the grief work had been done so effectively that the patient has emancipated herself and the readjustment must now be directed towards new interaction” (Lindemann, 1944-45, p. 148). It appears that Lindemann’s prior work on grief influenced his conclusions concerning anticipatory grief.

Limitations of Lindemann’s conceptualisation

It has been argued that the methodological limitations of Lindemann’s study are such that it would not satisfy current standards (Stroebe & Stroebe 1987). There are three major problems. Firstly, it was based on anecdotal material (Ball 1977; Parkes 1970). Secondly, individuals included in the sample were not simply reacting to a routine death. Some of the bereaved individuals had been traumatised by personal involvement in a fire disaster. Other participants were psychoneurotic patients who, during the course of their treatment, had experienced the death of a relative. Finally, no operational criteria were provided to define normal, pathological or anticipatory grief. In addition to these limitations a number of important questions remain unanswered. For example, how many patients in the sample were relatives of members of the armed forces? Did all members of this sub-group exhibit the syndrome? If not, what was the breakdown of those who experienced anticipatory grief and those that did not? Was there a gender difference? Did the service personnel facing their own anticipated death exhibit the same syndrome, and, if not, why not? Who were Lindemann’s clients — the wives or the returned servicemen? How was this group of

people selected? Were they initially referred for psychiatric management of other problems? What were the possible alternative explanations for the observed behaviour?

Although acknowledging that the effects of wartime separation had been previously reported by Rosenbaum (1944), Lindemann (1944-45) omitted to discuss the implications of Rosenbaum's findings. Two significant issues that were highly relevant to Lindemann's argument were noted in Rosenbaum's article. Firstly, that it was "... only natural ... for a young wife to become mildly and temporarily depressed when her husband goes off to war" (Rosenbaum 1944, p. 338). Secondly, it provided case studies of apparent grief reactions to wartime separation that were, in fact, responses to earlier losses that had not been previously acknowledged. Unfortunately, Lindemann gave no indication whether his patients' histories were investigated for previous losses or their reaction to such losses. Consequently, the reader is left to speculate on what were the differences between Lindemann's anticipatory grief and the experience of Rosenbaum's informants.

Lindemann (1944-45) also claimed that the phases of anticipatory grief were the same as normal grief. However, the pathognomonic attributes for each type of grief, described in his article, are not identical. One of the major differences is that Lindemann (1944-45) claimed that normal grief is behaviourally expressed through the loss of patterns of conduct. However, Lindemann (1944-45) did not indicate whether or not this behaviour occurred during anticipatory grief. The disparity between these two situations leaves the reader pondering the following possible alternatives. Firstly, Lindemann (1944-45) simply failed to provide examples relating to the loss of patterns of conduct for individuals experiencing anticipatory grief. However, this is unlikely since none of the four points mentioned as phases of anticipatory grief imply loss of patterns of conduct. Secondly, if there is no such conduct pattern loss then the two 'syndromes' have different symptomatologies and, therefore, are either distinctly different types of 'grief' or the 'anticipatory' reaction is not grief. In fact, there is only one clear similarity between the two situations: preoccupation with the image of the person from whom the individual is separated, either by death or war service. The other attributes of each type of grief are not identical. A more discursive option is that, despite sharing some common or similar symptoms with normal grief, the phenomenon individuals experience while separated from close family members who are under the threat of death is not grief but is something quite different. It has been argued that

labelling the events that precede the death of a spouse as anticipatory grief is arbitrary and misleading (Weiss 1988).

Furthermore, Lindemann's (1944-45) conclusions have been criticised for failing to acknowledge possible alternative explanations for a wife wanting to divorce her husband after a separation (Clayton, Halikas, Maurice & Robbins 1973). For example, Freud's discussion of anxiety, originally published in 1926, provides a plausible explanation for the wife's actions. In essence, Freud argued that anxiety was the reaction to the danger of losing a loved object. The pain of mourning was the reaction to the actual loss of the object, and defence mechanisms were a mode of dealing with anxiety and pain (Bowlby 1975). It can be argued, therefore, that it is more likely that Lindemann's (1944-45) subjects were responding to separation anxiety generated by the entry of their family member into the armed forces rather than preoccupation with a fantasised possible future event - death. Based on Freud's theory, the individual would be expected to respond to their experience of separation anxiety with any one of a number of defence mechanisms that could lead to the breakdown of the marital relationship. For example, the wife may defend against the anxiety caused by the separation from her husband by denying she has strong feelings of attachment to him. In turn, the wife's use of denial as a defence mechanism may result in the behaviour that makes her appear remote or detached from her returning husband.

Unfortunately, Lindemann (1944-45) limited his discussion of anticipatory grief to women facing the possible death of male family members on active military service. No indication was given as to whether soldiers facing the possibility of their own death in battle engaged in the same process. Lindemann restricted his application of anticipatory grief to wartime separation experiences and at no time examined the more certain prospect of loss associated with diagnosis of a terminal illness.

Further development of anticipatory grief

Despite the obvious limitations of the original presentation of anticipatory grief the prospect of discovering its outcome and developing and applying meaningful therapeutic intervention during its process captured the imagination of researchers and therapists (Rando 1986a; Siegel & Weinstein 1983). More recently, its application has been broadened to include terminal illness (Aldrich 1974; Rando 1986a) and HIV/AIDS (Cho &

Cassidy 1994; Kelly & Raphael 1992). However, generalisation to these situations has been made without the benefit of empirical evidence (Rando 1986a). Furthermore, such generalisation has introduced critical changes in the concept's meaning from Lindemann's (1944-45) original explanation, which involved concern with future adjustment *after* a perceived likely death, to the current omnibus definition that it is any grief occurring *prior* to a perceived inevitable loss (e.g., Aldrich 1974; Kalish 1985; Knott & Wild 1986; Rando 1983, 1984).

In reviewing empirical studies of anticipatory grief Fulton & Gottesman (1980) grouped the research into 'children' and 'adult' studies. The use of this classification system clearly illustrates the shifting perspective taken by investigators and the changes in terminology arising from a broadening in scope of the concept's definition and meaning. Early studies were mainly associated with parental responses to the terminal illness of a child (e.g., Bozeman, Orbach & Sutherland 1955; Chodoff, Friedman & Hamburg 1964; Friedman, Chodoff, Mason & Hamburg 1963; Richmond & Waisman 1955). Binger et al. (1969) interviewed parents after their child's death, as did Rando (1983), whereas Futterman et al. (1972) conducted interviews both before and after the death. As such, these studies related to a situation best described as 'forewarning of loss' and perceived anticipatory grief as one potential coping mechanism of parents. More recent studies (e.g., Ball 1977; Clayton et al. 1973; Gerber, Rusalem, Hannon, Battin & Arkin 1975; Hill et al. 1988; Maddison & Walker 1967; Parkes 1964, 1970, 1975; Sanders 1982-83), primarily involving adult bereavement, labelled all discussions of forewarning of loss as investigations into anticipatory grief (Fulton & Gottesman 1980). Moreover, these later 'adult' studies, primarily conducted after the death of a close family member, examined the post-mortem value of anticipatory grief (Fulton & Gottesman 1980). The experiencing of anticipatory grief was conceptualised as having immediate positive effects on current coping as well as providing long-term beneficial effects on the adaptation of the individual after the death of the family member. In this way, the current usage of the concept, with these adaptive coping connotations, represents a marked deviation from the original concept.

Methodological and conceptual issues

Debate concerning the benign, adaptive, or emotionally harmful effects of experiencing anticipatory grief has continued within the literature and resulted in the accumulation of

inconsistent information (Rando 1986a). A number of explanations for these contradictory and inconclusive research results, primarily based on methodological, research design and definitional issues, have been proposed.

Methodological issues

Many of the methodological problems associated with anticipatory grief research are common to most areas of applied psychological research. For example, reviewers of anticipatory grief research have identified the most crucial problems as (a) the wide differences in methodologies, and parameters that preclude comparability of results (Fulton & Gottesman 1980; Rando 1986a, 1988; Siegel & Weinstein 1983); (b) the design of research projects (Rando 1988); (c) the inadequate operational definitions that limit validity (Fulton & Gottesman 1980; Rando 1986a, 1988); and (d) the false assumptions on which empirical studies are based (Rando 1986a, 1988).

Methodologies and parameters

The empirical studies examining anticipatory grief have been criticised for the significant variations among samples used (Fulton & Gottesman 1980; Rando 1986a; Siegel & Weinstein 1983). The main differences between samples include sex, age, relationship to the deceased and amount of advanced warning. Not all researchers have provided data on the gender of their sample. However, of those who have provided this information, some have confined their investigations to widows (e.g., Ball 1977; Hill et al. 1988; Maddison & Walker 1967; Parkes 1964, 1970), others have used both widows and widowers (e.g., Clayton et al. 1973; Gerber et al. 1975; Parkes 1975), while still other researchers have claimed that there is no significant difference between the grief reactions of widows and widowers (Glick, Weiss & Parkes 1974).

Similarly, there is a wide age variation in the samples used. Some researchers have chosen to examine the effects of anticipatory grief on individuals with an average age less than 50 years (e.g., Parkes 1970, 1975; Welch 1982). Other researchers have concentrated on individuals whose average age was greater than 50 years (e.g., Clayton et al. 1973; Gerber et al. 1975; Hill et al. 1988; Parkes 1964; Sanders 1982-83). Still further researchers used samples with an age range from early 20s to late 80s (e.g., Ball 1977; Futterman et al. 1972; Rando 1983). Some researchers (e.g., Maddison & Walker 1967) did not provide data on the age of their sample.

Relationship to the deceased is another variable that has changed significantly in the empirical studies. Although most of the more recent studies have involved examination of the effect of anticipatory grief on spouses (e.g., Ball 1977; Clayton et al. 1973; Gerber et al. 1975; Hill et al. 1988; Maddison & Walker 1967; Parkes 1964, 1970, 1975), some researchers have included in their sample, individuals with a wide variation in relationship to the deceased. For example, Welch (1982) included in her sample people who were either a spouse, child, sibling, or niece of the deceased. On the other hand, as Fulton and Gottesman (1980) have pointed out, most of the early studies in anticipatory grief concentrated on the reactions of parents to the terminal illness of their child (e.g., Binger et al. 1969; Bozeman et al. 1955; Chodoff et al. 1964; Friedman et al. 1963; Natterson & Knudson 1960; Richmond & Waism in 1955).

Although much of the empirical research into the effects of anticipatory grief has discussed the effect of advanced warning on the post-mortem grief, the temporal definition of advanced warning has been a variable that has changed considerably. Some studies have not provided sufficient data on time frames for advanced warning (e.g., Binger et al. 1969; Futterman et al. 1972; Maddison & Walker 1967; Parkes 1964, 1970). Those researchers who did define an advanced warning time frame failed to agree on a set period. Furthermore, they did not provide adequate reasons for the particular choice of time limits. Some researchers suggested that individuals whose death occurred in less than five days, after the onset of an illness, constituted a sudden death (e.g., Ball 1977; Clayton et al. 1973). Other researchers expanded the sudden death time frame to include deaths that occurred in less than two weeks (e.g., Parkes 1975), one month (e.g., Hill et al. 1988), less than two months (e.g., Gerber et al. 1975) and less than six months (e.g., Welch 1982). Sanders (Sanders 1982-83) failed to define sudden death but indicated that a short-term chronic illness was of less than six months duration and a long term chronic illness was greater than six months.

Research design issues

There are two aspects of research design that are influential in the empirical development of anticipatory grief. Firstly, all but one empirical study (e.g., Welch 1982) have been designed to gather data after the fact rather than examining the issue as it was occurring. Secondly, the design objectives of empirical studies have been rarely developed to focus

specifically on an examination of anticipatory grief. Generally, anticipatory grief has been included as a minor aspect of the overall study.

This significant change in methodology, from focus on the parents of terminally ill children to the post-death examination of adult experiences prior to an adult death, had serious consequences for the empirical development of anticipatory grief. Virtually no recent studies have undertaken investigation of anticipatory grief during the dying trajectory, that is, during the individual's course of dying (Glaser & Strauss 1968). Although there is a widely held belief among many researchers and health care professionals that it is neither ethical nor moral to conduct research during the terminal phase of an individual's life, this claim has been refuted by Fulton (1989b). In a study that examined the needs of the terminally ill, from both the patient's and nurse's perspectives, Fulton found that the individual with the terminal illness not only willingly agreed to participate, but was pleased to think that they were able to give something of themselves during this period when they were receiving so much from others. Furthermore, Fulton found it was the health care professionals, particularly palliative care nurses, who were very protective of 'their' patients and tried to shield them from involvement in the study (Fulton 1993).

The adult studies have generally failed to heed the early warning by Bozeman et al. (1955) which was reissued in the mid 1970s (Epstein, Weitz, Roback & McKee 1975), concerning the serious weakness in conducting research after the fact, particularly when strong emotions were involved. Bozeman et al. (1955, p. 3) were justifiably concerned about data that resulted from selective emphasis of subjects since "... recall of complex affectively laden events is more construction than reproduction". The situation is further complicated by the variable length of time after death some interviews were conducted. Although most researchers who were involved with post-mortem interviews conducted these within the first 12 to 15 months after the death (e.g., Ball 1977; Clayton et al. 1973; Gerber et al. 1975; Hill et al. 1988; Parkes 1970, 1975), some researchers conducted interviews as long as three years after the death (e.g., Rando 1983). To suggest that emotive data gathered after this period of time was a faithful reproduction of actual affect, or events, is questionable. The current research addresses this issue by including individuals who have been diagnosed with a life-threatening form of cancer or HIV/AIDS as informants in the research.

Another factor influencing the conceptual and empirical development of anticipatory grief has been the focus of the design objectives of relevant research. There is a dearth of empirical research with the primary focus of the design objectives developed to clarify issues relating specifically to anticipatory grief. The more common experience has been that articles purporting to be empirical studies into aspects of anticipatory grief have arisen from larger studies. There are a number of projects that fall within this category, (e.g., Binger et al. 1969; Chodoff et al. 1964; Clayton et al. 1973; Friedman et al. 1963; Futterman et al. 1972; Gerber et al. 1975; Glick et al. 1974; Maddison & Walker 1967; Rando 1983; Sanders 1982-83). The design objectives of these major studies have been developed to have as their primary focus either a wide range of grief issues, or general questions other than anticipatory grief. However, since some aspects of anticipatory grief have permeated the results of these larger studies, researchers have taken the opportunity to develop a number of articles to cover the range of issues, including anticipatory grief. For example, a study was conducted in 1968-1969 involving a number of researchers examining a wide range of grief issues. In this study, 109 white widows and widowers were interviewed using a systematic interview with questions dealing with the physical and mental health of the survivor. Questions attempting to assess the marriage and social network of the survivor were also included. At least four different papers resulted from this study (e.g., Bornstein, Clayton, Halikas, Maurice & Robbins 1973; Clayton et al. 1971; Clayton, Halikas & Maurice 1972; Clayton et al. 1973). While all four reports arose from the same study, the authors of each article implied that the research design objectives were specific to the study reported in that article. None of the articles actually reported the overall research design objectives of the major study. The current study addresses this question by focussing on collecting data on individuals' perception of their experiences of living with a life-threatening disease and who are facing their impending death.

The problems associated with the above mentioned type of research are augmented when consideration is given to the operational definitions developed for each 'study'. For example, Clayton et al. (1972), in a paper on depression used specific criteria, "... a constellation of depressive symptoms" (p. 47), to define depression in their subjects. In a later paper on anticipatory grief (Clayton et al. 1973) the same criteria was used to define two different phenomena. The presence of this cluster of depressive symptoms during the terminal illness defined "... an anticipatory grief reaction" (p 48). If the same cluster of

symptoms was present following the death of a spouse it was considered as "... a normal depressive reaction" (p. 48).

An example of anticipatory grief issues permeating the results of a very different study is that of the major study, undertaken in the early 1960s, which investigated the adrenal cortical response under conditions of chronic stress. This study was also undertaken by a number of researchers. Although the design objectives of the major study focussed on the effects of chronic stress, aspects of anticipatory grief were claimed to be present in the study because of the stress situation chosen. The subjects were parents of children with neoplastic disease, mainly leukemia. Friedman et al. (1963) and Chodoff et al. (1964) published papers on slightly different aspects of coping behaviour of the parents. Both briefly discussed aspects of anticipatory grief.

Although Friedman et al. (1963) specified that their paper was concerned with "... the clinical impressions gained over a 2-year period while this study [on adrenal cortical response] was in progress" (p. 610), they proceeded to provide information that created the impression that their conclusions were based on empirical research designed specifically to collect data on the behaviour of parents anticipating the death of a child. It is clearly evident, from the way these authors presented their material, that the original, larger study design was not adequate for the collection of the necessary data relating to anticipatory grief. For example, no numbers were provided to support their conclusions. They fall back on generalisations such as 'majority' and 'minority' in discussing their results. The research design, as reported in their article, also supports the belief that their original design objectives for the larger study did not take into account the necessity to gather reliable data to enable them to discuss aspects of anticipatory grief in a meaningful way. For instance, the subjects were treated differently, in that they were given different numbers of interviews, some were seen on an outpatient basis, and, consequently, seen fewer times than those parents living in the hospital with their child. There was insufficient information provided on the types of interviews held, the content of those interviews, and no statistical data collected. Also, no operational definition was provided for anticipatory grief, yet the researchers discussed this phenomenon.

The major problem with this type of 'study' is not in its unsound methods nor in its conclusions being based on 'clinical impressions'. Rather, the problem resides in how the knowledge arising from the published findings are used to support later studies. Friedman et al. (1963) provided a clear warning about their conclusions being based on clinical impressions. That is, the conclusions, made in their paper, were not substantiated by actual empirical data. However, later researchers appear to have chosen not to emphasise the conditions under which the study conclusions were drawn. They appear to have chosen simply to use these empirically unsubstantiated conclusions to support their own studies.

A further issue that has been largely overlooked in anticipatory grief research design is the inclusion, as subjects of the research, of the individuals themselves who are dying. Although discussions concerning anticipatory grief frequently include people who are dying (Siegel & Weinstein 1983) relatively little research has been undertaken with the terminally ill person themselves (Bergeron & Handley 1992; Hayslip et al. 1991-92). This would appear to be in response to the widely held belief among many health care professionals and researchers that it is neither ethical nor moral to conduct research with an individual who is in the terminal period of their life. The current research addresses the deficiency in previous research by interviewing individuals facing their own impending death through either cancer or HIV/AIDS.

Operational definitions

Anticipatory grief and adjustment to loss are complex subjective experiences not particularly amenable to quantification (Fulton & Gottesman 1980). Furthermore, as these authors point out, there has been no uniformity in the operational definition of the concept, or the measurements used in its investigation. In a limited review of the literature O'Bryant (1990-91) claimed that anticipatory grief has been operationally defined in two ways. Firstly, the length of illness is used as a measure of anticipatory grief. Secondly, forewarning of impending death is equated with anticipatory grief. That is, it is operationally defined in terms of whether knowledge is available concerning the person's impending death.

Although Fulton and Gottesman (1980) claimed that it has been a typical practice to operationally define anticipatory grief according to the length of time of the patient's

terminal condition, scrutiny of the reviewed studies reveals that this is not an entirely accurate assessment. In their review, Fulton and Gottesman (1980) referred to ten studies relating to anticipatory grief. A number of these research studies did not provide any definition of anticipatory grief but appeared to accept Lindemann's concept without question (e.g., Friedman et al. 1963; Maddison & Walker 1967; Natterson & Knudson 1960). Furthermore, two studies provided a definition not based on the length of illness (e.g., Clayton et al. 1973; Futterman et al. 1972) or assumed anticipatory grief was implied by the appearance of certain behaviour patterns (e.g., Binger et al. 1969). The remaining four empirical studies, quoted by Fulton and Gottesman (1980), relied on length of illness as a definition.

On closer examination, however, two of the studies using length of illness as a definition were not about anticipatory grief but were actually focussed on forewarning of loss (e.g., Glick et al. 1974; Parkes 1975). Neither of these two studies discussed the expression of grief prior to the expected loss. Thus, only two of the reports quoted by Fulton and Gottesman (1980) actually used length of illness to define what the respective researchers called anticipatory grief (e.g., Ball 1977; Gerber et al. 1975). Although ostensibly claiming to be concerned with anticipatory grief, both these projects discussed opportunity for anticipatory grief, but, in fact, were examining the effects of forewarning of loss. To confuse the situation further, both these studies were based on the false assumption that knowledge of impending loss (in his case death) equalled anticipatory grief. That is, knowledge of an impending loss equates with the expression of grief for that future loss. (This issue is examined in more detail under the heading 'Conceptual confusion' on page 37.)

The studies that have defined anticipatory grief, including those undertaken since publication of the review by Fulton and Gottesman (1980), have done so in very different ways. While all these definitions have been unique, they can be broadly grouped according to their emphasis, for example behavioural (e.g., Binger et al. 1969; Futterman et al. 1972; Hill et al. 1988; Rando 1983), and affective (e.g., Clayton et al. 1973; Sanders 1982-83; Welch 1982).

Basic assumptions underlying empirical studies

There is little doubt that the above factors have had a significant influence on the development of empirical studies on anticipatory grief, and the conclusions drawn from data collected in these studies. However, the critical issue that has been overlooked is that the concept is based on questionable assumptions.

Although the concept was introduced in 1944, it was not until the early 1980s that serious questions were raised about the underlying assumptions which formed the foundations for the concept, and the ready acceptance of anticipatory grief as a valid clinical phenomenon. Fulton and Gottesman (1980) traced two assumptions about anticipatory grief to its development within the traditional psychoanalytic perspective. The first assumption was that all those in a particular state of bereavement experience a comparable volume of grief. The second assumption was that once grief work began, the grief reaction was dissipated in a continuous and irreversible path toward resolution. Fulton and Gottesman (1980) argue that these assumptions are limiting in that they do not give adequate consideration to alternative approaches to investigation of the phenomenon currently known as anticipatory grief. For example, Fulton & Gottesman (1980) suggest that a psychosocial examination of the issues is relevant.

Siegel and Weinstein (1983) were critical of the limited conceptual and empirical underpinnings of Lindemann's concept. Furthermore, they were critical of the widespread acceptance of the concept and its enduring appeal for clinicians given that the empirical foundations of anticipatory grief are so unclear. Also, they drew attention to the fact that little is known about the frequency with which the phenomenon occurs.

Rando (1986a, 1988) suggested there were two major misconceptions which influenced the development of anticipatory grief. The first was an over focus on death as the ultimate loss, with its consequent disregard, or at the very least, lack of sufficient appreciation, of other losses inherent in a fatal diagnosis and terminal illness. What many researchers fail to recognise is that the effect of current losses associated with a terminal illness (e.g., loss of lifestyle, loss of health, loss of role, loss of control, loss of personal independence, loss of normal family life, loss of income, loss of friends, loss of social contacts, loss of dreams, hopes and expectations, and loss of privacy) does not decrease simply because researchers

choose not to recognise their existence. Individuals are faced with variations of this multitude of losses and are likely to respond to them in a variety of ways, including using any one of a number of defence mechanisms, or accepting the reality of the losses and expressing their grief for the recognised loss, or alternating between both these situations. The second major assumption, also stemming from the psychoanalytic background of anticipatory grief, was that the experience necessarily involved a major deathecis from the dying individual. This assumption stems directly from the previously outlined implicit assumptions in Lindemann's original 1944 article.

Perhaps the most important underlying assumption in all the research about anticipatory grief is that it exists and, therefore, must be part of the subjective experiences of individuals living with a life-threatening illness. This belief is evidenced in the fact that the critical question guiding empirical work has been "... not whether anticipatory grief exists but whether it is psychologically useful in mitigating the post-mortem grief of the survivor" (Clayton et al. 1973, p. 47). This statement reflects the continuing confidence in the validity of the concept and a firm belief that future empirical research should be directed toward learning more about its implications for the mental and physical health of the survivor-to-be (Kastenbaum & Costa 1977). More recent support for this approach is evidenced in the claim that the semantic argument over the terminology of the experience is irrelevant to its existence and to the necessity of providing assistance (Rando 1986a). However, this approach confuses the two very different processes of identifying and clarifying a phenomenon and developing an accurate nomenclature to describe that event.

Another implicit assumption, embodied in the approach to anticipatory grief research, has been that understanding how post-mortem grief can be decreased is more important than developing a clear conceptual understanding of what it is that occurs to individuals either facing their own imminent death or the inevitable death of a close family member. This approach to empirical research reflects the readiness with which health carers respond to the value that it is important to mitigate emotionally painful experiences surrounding death and loss (Siegel & Weinstein 1983). More significantly, it ignores the importance, for the growth of scientific knowledge, of solving empirical problems and what Laudan (1977) refers to as the higher order conceptual problems concerning the well-foundedness of conceptual structures which have been devised to answer empirical questions. The current

research addresses this issue by examining how individuals make meaning of their experience of living with a life-threatening disease, what future they imaginatively construct for themselves and how they respond to their thoughts about these imagined futures.

Conceptual confusion

Perhaps the most significant factor influencing the theoretical and empirical development of anticipatory grief has been the lack of conceptual distinction between 'anticipatory grief' and 'forewarning of loss' (Fulton & Gottesman 1980; Rando 1986a; Siegel & Weinstein 1983). Combined with this conceptual confusion is the propensity of researchers to consider a number of terms as identical and, consequently, to use them interchangeably. Moreover, the usage of these terms is not consistent. As has been detailed previously, some researchers use the one term 'anticipatory grief' as an explanation for observations or hypothetical constructs for which other researchers and clinicians use more specific terms. This practice represents an equivocation in the use of the term 'anticipatory grief'.

Fulton and Gottesman (1980) were the first to point out that researchers used the terms 'forewarning of loss' and 'anticipatory grief' interchangeably. The assumption that these two concepts are identical is based on the misconception that when a person is anticipating a death, and is not denying its advance, that individual is also engaging in a process that is referred to as anticipatory grief (Rando 1986a; Stroebe & Stroebe 1987). That is, knowledge of impending death is equated with the expression of grief. It is assumed that if the individual knows about the impending death then that individual must be, or should be, grieving. A prevailing belief associated with this idea, and one that has been accepted as one of the values of the institution of health care concerning grief theory, is that if the individual is not expressing their grief, either normal or anticipatory, then they are using denial in a maladaptive way (Reeves 1974; Smith 1993). However, empirical evidence exists that contradicts the assumption that denial is maladaptive. In a longitudinal study of widows, Parkes (1970) found that in most cases the wife's denial of the seriousness of the situation prior to the husband's death enabled her to interact with her dying partner without overtly breaking down. Parkes did not consider this response maladaptive. Furthermore, from a rational perspective, it is clear that not all persons will necessarily feel the same way about the impending loss of someone with whom they have a close relationship. While one

person may be very upset at the prospect of separation from a partner, another may be indifferent or even welcome the prospect of separation.

The conceptual confusion intrinsic to anticipatory grief research centres on the basic terms: forewarning of loss, anticipation of loss, opportunity for anticipatory grief, and anticipatory grief. The confusion has been aggravated by the way in which studies have tended to focus on specific aspects of the grief experience. For instance, some studies focus predominantly on cognition (Gerber et al. 1975), some on affect (Clayton et al. 1973), and others on behaviour (Chodoff et al. 1964; Rando 1983), while ostensibly investigating the overall aspects of anticipatory grief. In an effort to overcome this bias, some authors (Fulton & Fulton 1971; Rando 1986a) have used a comprehensive approach which incorporates elements of cognition, affect and behaviour.

Although no studies have addressed the issue of distinguishing between the above mentioned terms, Sweeting and Gilhooly (1990) suggest that it is important to clarify conceptually-based problems before investigating their impact. Fulton and Gottesman (1980, p.51) defined forewarning of loss as "... the perception that a death is likely to occur". This means that the individual concerned, whether it be the patient or a 'significant other', depending on who is the person under study, has the knowledge or awareness that death is likely to occur. Yet, such forewarning does not indicate whether anticipatory grief will necessarily follow. It is possible that a situation of mutual pretence might exist, that is, each party might define the patient as dying but each pretends the other has not done so (Glaser & Strauss 1965). It is also possible to have the knowledge that death is a highly probable outcome, but refuse to accept this possibility. This view is supported by empirical evidence (Parkes 1970; Silverman 1974; Vachon, Freedman, Formo, Rogers, Lyall & Freeman 1977). Described in these terms, forewarning of loss is actually a knowledge-based concept. It is defined in terms of the sender rather than the receiver of the information: the message having been sent, it is presumed to have been received, even though the information may not be fully acknowledged by the receiver due to its unpleasant nature. More importantly, being primarily cognitive, by definition, forewarning of loss does not necessarily include the generally accepted affective and behavioural components of grief. However, previous research has assumed anticipatory grief has occurred because of the fact that death is expected (Sweeting & Gilhooly 1990).

The term 'anticipation of loss' is similar to 'forewarning of loss' in that it is cognitively based. Belief in an impending loss comes before the anticipation of its affect. That is, the person may have reason to believe that they will encounter a loss at some time in the future. This belief may be based on information obtained from another source considered to be authoritative (e.g., medical practitioner or specialist). Alternatively, the information may be based on the individual's interpretation of specific, personally experienced, signs and symptoms. Having arrived at this belief individuals may respond to this 'knowledge' in a variety of ways: they may, or may not, continue to behave as they had prior to receiving the knowledge of impending loss; they may react by using defence mechanisms (e.g., intellectualisation, denial); they may fully acknowledge the significance of the loss yet still not give vent to their emotions of grief. Consequently, the term 'anticipation of loss' does not signify the expression of grief.

The term 'opportunity for anticipatory grief' does not indicate whether grief is being expressed. What it does describe is a situation in which the expression of grief could occur. It is similar to forewarning of loss in that the individuals concerned may have the knowledge that death will or is likely to eventuate within a given time frame. In this circumstance it would be a knowledge-based situation. It may not necessarily be behaviourally or emotionally expressed. Again, a situation of mutual pretence could occur (Glaser & Strauss 1965). The opportunity for expression of grief can exist without it being acted upon by the individuals concerned.

Similarly, it could be argued that a situation might arise where the opportunity for anticipatory grief exists, for example, closed awareness (Glaser & Strauss 1965). This is a situation where people external to the situation (e.g., health care professionals) may know of the patient's impending death and consider the opportunity for anticipatory grief is present, but the individual concerned may not be aware of the seriousness of the situation. On the other hand, the individual may be using any one of a number of defence mechanisms, (e.g., denial), as a response to the anxiety induced by their perception of danger. As discussed earlier, the use of defence mechanisms, such as denial, is not necessarily maladaptive behaviour (Simpson, 1979).

When introduced by Lindemann (1944-45), anticipatory grief referred to the expression of all the phases of grief in anticipation of the necessary adjustment after a possible death. Consequently, it involves not only cognitive aspects but also changes in affect and behaviour. However, the confusion revolving around terminology has been heightened further by the variation in definition of grief and related concepts that often reflects the professional discipline of the researchers.

The conceptual confusion of anticipatory grief research has been influenced by the lack of precise definitions within the general grief literature. Despite grief issues being the focus of considerable empirical inquiry for at least five decades, conceptual problems concerning the definition of grief and bereavement related concepts abound within the literature (Caroff & Dobrof 1975; Middleton et al. 1991; Rodgers & Cowles 1991). In particular, the terms 'grief' and 'bereavement' are often used interchangeably (Rodgers & Cowles 1991). Grief has been defined variously as "... the feelings of sorrow, anger, guilt, and confusion that can arise when you have suffered a loss or are bereaved" (Kalish 1985, p. 182); "... the emotional response to loss" (Raphael 1985, p. 33); and "... a psychological and physiological process that occurs in response to a specific loss" (Pine 1986, p. 39). Perhaps grief is best summarised by the definition of Stroebe and Stroebe (1987, p. 7) who perceive grief as "... the emotional (affective) response to loss, which includes a number of psychological and somatic responses". The current research adopts the definition suggested by Stroebe and Stroebe. A major implication of this definition is that a loss must occur prior to the expression of grief.

Anticipatory grief research has been further complicated by two definitions of 'mourning' that reflect the influence of the disciplines of psychiatry, and sociology. In the psychoanalytic literature, mourning is used to define an adaptive function where there is withdrawal of feelings, by the survivor, from the mental image of the deceased (Rando 1984, Raphael 1985). Frequently, on the other hand, the word mourning is used, in the sociological sense, to designate the culturally prescribed pattern of behaviour for expressing grief, or the conventional, institutionalised expressions of grief as determined by the mores and customs of the society, rather than as a synonym for grief (Averill 1968; Ball 1977; Kalish 1985; Stroebe & Stroebe 1987). However, through constant use, in different contexts, these two common meanings have become blurred, with the term mourning now

often being used interchangeably with that of grief, to depict either or both meanings (Bergeron & Handley 1992; Rodgers & Cowles 1991). This confusion of meanings frequently influences social interaction where each person uses the same word to refer to different reactions yet believe that each comprehends the other's situation.

Although mourning is prescribed by the society these socially imposed responses may not accurately reflect the individual's private expression of grief (Doka 1989). For example, the death of a partner in a homosexual relationship illustrates the discrepancies between community and individual responses that result in grief that is 'disenfranchised' by society (Doka 1989). In this situation individuals may experience grief at the death of their partner or close friend but have no socially acceptable way to express such emotion or become legitimately involved in socially defined mourning rituals. For example, Grief and Porembski (1988) found that although families engaged their gay son's lover in funeral planning, many then forbade the lover to attend the service. Other situations also exist where appropriate responses and outward expression of emotions are at best vague and ill-defined. Fulton and Fulton (1971) believe that this was the position regarding anticipatory grief.

Measurement of anticipatory grief

A specific attempt has been made at developing a tool for the measurement of anticipatory grief (Levy 1992). As with other empirical work on the concept of anticipatory grief, this research was also influenced by the previous social construction of the concept. Consequently, it failed to address the issues commonly influencing prior research. For example, it followed the customary course of interviewing individuals after the death of a spouse. Thus, it continued to ignore the previously issued warning that the recall of complex affectively laden events is more construction than reproduction (Bozeman et al. 1955; Epstein et al. 1975). Furthermore, the socially constructed knowledge concerning anticipatory grief was drawn on in the development of the instrument. As a result some of the questions are confusing and appear to be more relevant to grief for losses already incurred rather than anticipated losses. For example, one question included in the questionnaire (i.e., "Attempted to create a picture of your husband in your mind") implies that he is no longer present. Alternatively, the spouse responding positively to this item may be thinking of her attempts to recall his appearance prior to the illness. In this case she

would be responding to an actual loss rather than an anticipated loss. It should be noted also that the notion of 'attempting' to conjure up the images of the loved one does not pick up accurately on what is often reported to occur with mental images (i.e., the person can sense that the images just occur without any attempt to invoke them).

Reasons for non-critical acceptance

The conceptual understanding of anticipatory grief, and its empirical foundation, is so equivocal that the analytical practitioner is led to query why the concept has received such uncritical acceptance and why its appeal is so enduring for clinicians. It has been suggested that belief in an anticipatory grief which can mitigate the impact of ultimate death reduces the feelings of helplessness and personal vulnerability experienced by health care professionals who deal with dying patients and their families (Siegel & Weinstein 1983). Siegel and Weinstein (1983) suggest two situations that lead health care professionals to experience their own feelings of helplessness and personal vulnerability. Firstly, professional health carers can identify with clients and their profound, universal human experience of loss and grief. Secondly, they may experience the inevitable frustration arising from their own sense of mortality or inability to truly control their environment. Support for the notion of health care professionals facing shared issues in working with individuals with a life-threatening illness can be found elsewhere (Cho & Cassidy 1994; Kalish 1985; Siegel & Weinstein 1983).

Alternatively, when working with clients who are living with the impending death of a significant other, clinicians may observe what they expect to encounter. That is, a health care professional might expect a client to commence the grieving process in anticipation of the loss (Siegel & Weinstein 1983), or denial, in cases where there has been an absence of grief (Simpson 1979). Such expectations can be seen to develop from a spiralling process, emerging from an initial acceptance of the concept, leading to its greater use within the research literature, and the increasingly popular literature on grief. In turn, this leads to more widespread acceptance of the concept, thus leading more practitioners to adopt it as a principle underlying professional practice with terminally ill clients. As a consequence, the increasing number of health care professionals who adopt procedures based on the concept leads to more widespread acceptance of the concept and its validity. The durability of the concept is taken as additional evidence for its validity and thus clinicians' perceptions,

ultimately, are guided by their expectations (Siegel & Weinstein 1983; Simpson 1979) in what can be described as a bi-directional cyclical process.

Another explanation for the adoption of the principle of anticipatory grief rests on psychodynamic theory and therapy, where it is assumed that repressed information needs to be brought to consciousness in order that patients develop insight and awareness of their feelings and impulses, and that healthy behaviour necessitates expression of hitherto repressed, denied, or hidden feelings. To this end, the role of the health care professional is seen as one in which such processes ought to be encouraged in the patient. Recent emphasis on health promotion and prevention is also in keeping with the approach of having patients face and deal with issues at the earliest possible stage. However, the evidence for this approach being in the interests of all 'patients' is not available.

Misnomer or misconception

There is a limited number of researchers (e.g., Glick et al. 1974; Parkes & Weiss 1983; Silverman 1974) who have refuted the existence of anticipatory grief on definitional grounds. These authors suggest that if grief is defined as the psychological and physiological reactions to loss then anticipatory grief can not exist since the loss (death) has not yet occurred (Evans 1994). However, the problem with this argument is that it assumes that the only event of importance is the impending death.

In a paper examining the process of grief associated with an expected death, Bourke (1984) rejected the term 'anticipatory grief' because he believed that its original use was intended to denote a reaction to separation and the possibility of death rather than the inevitability of death associated with a terminal illness. Weiss (1988) argues that in so far as the term 'anticipatory grief' suggests a movement toward recovery from loss prior to the occurrence of the loss, the term is actively misleading. Furthermore, there is little in the developments that occur when anticipating a death that resembles the grief that will follow the actual death (Weiss 1988).

Rando (1986a), in a comprehensive article, pointed out that the term anticipatory grief was a misnomer because it suggested that grieving is solely for anticipated losses as opposed to past and present losses. To some people, grief implies complete decathexis from the dying

person. It has also been argued that loss can also occur in relation to the individual's hopes and expectations associated with that person in the future (Rando 1986a). Rando further stated that what occurred during the period of forewarning of loss was a more complex and multidimensional set of processes than had been previously recognised. Attempting to clarify the concept, Rando (1986a, p. 24) offered an alternative all-encompassing definition of anticipatory grief as:

... the phenomenon encompassing the processes of mourning, coping, interaction, planning, and psychosocial reorganization that are stimulated and begun in part in response to the awareness of the impending loss of a loved one and the recognition of associated losses in the past, present, and future.

However, by including coping, interaction, planning, psychosocial reorganisation and by proposing two perspectives, three time foci, and three classes of variables influencing anticipatory grief, Rando was no longer simply talking about grief as it has been more commonly defined, that is, as the response to a loss.

Rando (1986a) raised two important issues. Firstly, is the need to distinguish between grief being expressed for past and present losses and reactions to the future. This distinction has not been made in prior research on anticipatory grief. No account has been taken of whether individuals are responding to losses associated with the illness or other losses not associated with the illness. Secondly, is the issue that the period traditionally labelled as 'anticipatory grief' is a complex amalgam of other issues occurring in daily life needs to be addressed. Although raising some important issues, there are a number of ways that Rando's (1986a) proposals perpetuate the conceptual confusion that abounds in the anticipatory grief literature. Firstly, by continuing to suggest the problem is semantic rather than acknowledging the inherent conceptual difficulties. Secondly, by continuing to label this multidimensional experience as anticipatory grief, after cogently arguing that it is a misnomer. Finally, and most importantly, by confusing the expression of grief with the context in which it occurs. It appears that what Rando (1986a) was attempting to highlight was the fact that living with the knowledge of anticipated death is not simply a unidimensional experience of grief for future losses but, instead, occurs within the context of the complex amalgam of all the psychological, social, physical, and spiritual aspects of daily living. This may involve grief for past or current losses.

This argument is supported by other researchers who have moved beyond the biomedical model and suggest that grief must also be viewed from a sociological perspective. They have indicated that grief must be seen in the context of all the other threads in the fabric of a person's life rather than simply perceiving it to be the major factor (Averill 1968; Averill & Nunley 1988; Kellehear 1990; Mishler et al. 1981). The current research addresses these issues by adopting a different theoretical paradigm (symbolic interactionism) to examine what influences individuals' development of their subjective reality of living with a life-threatening disease, how they construct their imagined future and how they respond to these thoughts of the future.

Implications for health carers

The volume and content of literature now available on anticipatory grief attest to the fact that knowledge concerning the subject has become so established within the institution of health care that it now forms part of the body of generally valid truths or 'objective' reality of terminal illness. This has led to the development of institutionally defined 'appropriate' and 'inappropriate' responses for individuals, family members and health care professionals. Some of these appropriate responses for the dying individual have been openly stated (Noyes & Clancy 1977). However, others are implied in research projects (e.g., Welch 1982) and the educational literature for health care professionals (Cho & Cassidy 1994; Rando 1983). For example, it has been stated that dying patients need to be as consciously alert as the progress of their illness will allow to enable them to "... communicate with intimate loved ones while completing their practical 'unfinished business' that can enable an easier acceptance of death" (Peterson et al. 1992, p. 348). Furthermore, in providing solutions to a clinical example concerning anticipatory grief, it has been asserted that the health carer's short-term and long-term goal statements, respectively, would be "... the patient will be relieved of the immediate anxiety" and "... the patient will resolve his grief through a constructive process relating to the diagnosis of a possible terminal illness" (Peterson et al. 1992, p. 359).

There are a number of implicit health care-based assumptions contained within these statements. Some of these assumptions relate to the patient and family, others relate to the health care professional. These implicit assumptions also influence the development of therapeutic intervention programs. It is implied that the goals of the patient and family are

to (a) accept the impending death, (b) complete all unfinished business prior to death, (c) resolve all family emotional problems irrespective of their prior duration, (d) 'grow' spiritually through the experience (Humphrey 1986), and (e) take advantage of each and every opportunity, with health care professionals, to discuss emotional issues and concerns. However, any radical departure from the institutionalised order is seen as a departure from reality and designated as 'mental disease' (Berger & Luckmann 1971). Consequently, the individual who does not respond in the expected manner is considered 'deviant' and in need of therapeutic intervention. The most common expression of this 'deviance' is said to occur in the form of 'denial' (Glaser & Strauss 1965; Peterson et al. 1992; Rando 1984). However, this raises the important question of whose reality is being denied. Is the individual denying the health care professional's reality? Is the health care professional denying the individual's reality?

Also buried within these statements are assumptions relating to health care professionals. These are (a) it is the health carer's responsibility to develop the appropriate therapeutic intervention, (b) the health care professional will have the skills and knowledge to intervene successfully, and (c) the family's failure to resolve all their issues results from the health care professional's failure to maintain adequate communications. In fact, it has been concluded that it is the health professional's role to help families "... maintain grief responses within normal and masterable boundaries" (Welch 1982, p. 156). However, Welch provided no descriptions or definitions of what constituted "... normal and masterable boundaries".

Continuing to use anticipatory grief in the expansive manner suggested by Rando (1986a) encourages health care professionals to continue making assumptions about the experience of individuals living with the knowledge of their impending death. For example, health carers regularly perceive the appearance of tears in these patients as an expression of grief rather than an indicator of alternative emotions such as fear, anger, or frustration. Furthermore, it neglects the sociological literature which suggests alternative concepts such as, uncertainty, illness careers or trajectories, stigma, biographical work and reconstitution of self, managing regimes, information awareness and sharing, and family concerns, which can facilitate understanding of the individual's experience of illness (Conrad 1987).

Summary

The ascendancy of the social institution of medicine, as the dominant force shaping and embodying Western culture's death fears and immortality hopes, has influenced the development of knowledge about grief and, in particular, knowledge concerning anticipatory grief. In its original presentation the concept of anticipatory grief was applied to an individual's attempt to resolve concerns with future adjustment that might occur after a perceived, likely death. The article introducing the concept was premised on the positivist understanding of social reality. This positivist paradigm formed the foundation for subsequent empirical studies related to anticipatory grief. Furthermore, it was the firm belief in the doctrine of positivism that led to the unquestioning acceptance of the concept. Consequently, empirical studies concerning anticipatory grief have been primarily focussed on discovering the effects of its outcome and developing and applying meaningful therapeutic intervention during its assumed process rather than establishing the validity of the phenomenon.

Although application of the concept was theoretically broadened in the early 1970s to include individuals with a terminal illness, it was not until the late 1980s that the concept was applied to an examination of the effects of anticipatory grief on individuals who had a family member die from a terminal illness. However, generalisation to these situations has been made without the benefit of empirical evidence. These developments introduced critical changes in the concept's meaning to the current omnibus definition that it is any grief occurring prior to a perceived inevitable loss.

Debate about the benign, adaptive or emotionally harmful effects of anticipatory grief has continued within the grief literature and resulted in the accumulation of inconsistent findings. These contradictory and inconclusive research results have been attributed to the wide differences in methodologies and parameters that preclude comparisons, the deficiencies in design of research projects and the false assumptions on which empirical studies are based. Furthermore, the lack of conceptual distinction between anticipatory grief and forewarning of loss has influenced the theoretical and empirical development of anticipatory grief. In addition, the lack of distinction between grief for past losses, grief for current losses and reactions to thoughts about the future have contributed to further conceptual confusion.

Although more recently questions have been raised concerning the validity of the concept they suggest that the problem is primarily one of semantics. A theoretical argument has been presented that the term is a misnomer but the phenomenon still exists. However, this argument, also grounded in the positivist paradigm, fails to acknowledge the possibility of an alternative way of conceptualising the experience of individuals living with a life-threatening illness. This thesis redresses this imbalance by using a different theoretical paradigm to conceptualise the problem.