

A Review of the grief process and bereavement follow up support.

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STATEMENT OF SOURCES

This thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma.

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All research procedures reported in the thesis received the approval of the relevant Ethics/Safety Committees.

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ABSTRACT

Grief is a life changing and universal experience, expressed through individual sets of responses and behaviours. Society and health workers' interpretation and beliefs regarding grief and bereavement have changed throughout the decades. This is a continually evolving process. As we move into a new century, so too does grief move into a new era where a new postmodern paradigm is arising. We are thus deviating away from stage theories that are time limited, linear and predictable.

Emphasis in this new wave of thought is placed upon grief as an oscillating and highly unique experience, one that encourages a continuation of a bond and lifetime relationship with the deceased. This current qualitative study explores the new phenomenon in relation to both the grief process and bereavement support programs, by extensively reviewing the literature and analysing data from a number of interviews with the bereaved. Furthermore the supports offered by society, with particular focus on a Melbourne Community Bereavement Follow Up Program, are reviewed.

By observing and discussing expressions of grief it was found, although unique and varying, some patterns or common behaviors emerged. Supports and comforts that assisted the bereaved are explored. Issues, including inappropriate comments and problems with bureaucratic departments, are also developed and discussed. There is an emphasis placed upon the need of health care staff and the community in general to increase their understanding of the grief process and bereavement support, so as to enhance care and practice when working with people who have suffered loss.

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Chapter One:

1.1 INTRODUCTION

“Bereavement is an almost universal experience and is viewed by the public as the most stressful life event” (Woof & Carter, 1997, p443). It is a vastly individual set of responses to loss, influenced by our cultural, religious and societal values. Our methods of embracing, interpreting and analysing grief and bereavement have changed over time, and no doubt will continue to evolve. In fact, Western society in the nineteenth century holds quite different views of the process and expression of grief to that of the twentieth century.

This qualitative research explores the grief process extensively, reviewing the emergence of classic and modern theories. Particular emphasis is placed upon the newly emerging paradigm which explores grief and bereavement from a postmodern perspective, whilst rejecting major elements of the earlier modernist models. Models such as the popular twentieth century stage models, declare grief as a linear, predictable and finite process, dominate the twentieth century literature, and have a great influence on education and practice in the area. The changes in appreciation which are emerging not only reject the above, but explore grief as an individual process with its aim not to be finite and bond breaking, but a process whereby one learns to live with grief, and is encouraged to embrace and enjoy a healthy relationship with the deceased.

This study explores the importance of this new mode of thinking, with relevance being placed upon a need for nurses in particular, and the community in general to increase their understanding of grief, thus enhancing theory and practice when dealing with the bereaved. This is a repetitive theme both in the emerging literature and in the findings of this research.

Questioned and reviewed in the current research data are the supports received from the community when a person is bereaved, with particular emphasis placed upon a review of participants perceptions of the bereavement support they have received. Investigating the supports offered in our society to assist the bereaved with their mourning helps us to identify the adequacy of such, with the hope to increase education and improve services when required.

Interest for the author arose from ten years experience nursing in the area of palliative care, the last few years in the community setting. As a nurse in the area, one builds bonds of all types with patients and their friends and families. As more experience was gained in palliative care nursing, the growing impression that grieving, dying and bereavement actually obey no rules was developed. There may be similarities in behaviour, even in expression, however it is apparent that this may be heavily influenced by how friends, family, culture, and society expect people to grieve and interpret their bereavement.

The author's personal belief, evident throughout this work, is that grief is a very individual process, without limits of time or certain behaviours. Death is often a very honest and humbling experience, and one which everyone is certain to be affected by. If people have a greater understanding of this, perhaps they can be more supportive and tolerant of the bereaved, understanding their needs and respecting individual expression. As Davies states, "No one can take away the pain of bereavement, but nurses can do much to facilitate optimal grieving, and they could do much more – if only they knew how" (1997, p4). The data gathered in this report supports this notion, but does not stop at nurses. Indeed, it recommends that many facets of our society and communities could benefit from such knowledge and skills.

This thesis will, in Chapter One, provide an overview of the definitions and aims of the work. Chapter Two reviews the literature, focusing on both classic and modern theories, leading into the more modern work of the new wave theorists. The research methods used in the study is explained in Chapter Three, with Chapter Four detailing the findings and discussions of the data obtained from the interviews. Recommendations and conclusions follow.

Defining words such as grief, bereavement and mourning has been attempted by many writers and theorists (Freud, 1917; Rando, 1984; McKissock, 1989; Leick & Davidsen-Nielsen, 1991; Parkes, 1993; Stroebe & Schut, 1995; Lev & McCorkle, 1998). It is no easy task, due to the complexity and diversity of the topic, and the way society uses them interchangeably. The task is to find a working definition, which specifically suits the perspective of the author.

“Bereavement – comes from a root word meaning shorn off or torn up,” (DeSpelder & Strickland, 1999, p224) indicating being stripped or suddenly deprived of something against the person’s will. Thus, the emphasis when defining bereavement is placed upon the loss of something significant, usually bringing about forced change.

Grief, according to Moules, is “the structural emotional, cognitive, social and spiritual change that occurs as a direct result of the experience of significant loss and that creates a mutable evolving, but lifelong relationship with the loss” (1998, p.6-7). Grief is generally considered the response to bereavement, and this includes perceptions, emotions and reactions. It is a natural and an individual healing process that is ever-changing, evolving and developing.

Grief is a universal experience, a reaction to loss as an irreversible event, and often thought of in negative terms such as distress, suffering, sorrow and anguish, as well as in terms of anger, relief and self-pity (DeSpelder & Strickland, 1999).

Mourning tends to be a word used interchangeably with grief, however it is defined in the literature as the cultural response or expression of grief (Rando, 1984; DeSpelder & Strickland, 1999). Bowlby describes mourning as both conscious and unconscious intrapsychic processes prompted by loss (1980). Its emphasis is on the behaviour of grief, the readjustment and incorporation in life. "Mourning is seen as a process actively engaged in by the bereaved rather than as a reaction to the loss" (DeSpelder & Strickland, 1999, p.225).

The aims of the research program are to:

1. Obtain in depth knowledge of the grieving process.
2. Review the client's perceptions of a bereavement program provided by a Palliative Care Service.
3. Describe participants' perspectives of the supports offered by the community to bereaved people.
4. Enhance the service provided by a Melbourne community bereavement program by the addition of further supports where appropriate.
5. Collect and analyse information regarding grief and bereavement in order to enhance nursing practice in general, particularly in the area of palliative care and oncology.
6. Provide an opportunity for those interviewed to share and reflect upon their experiences.
7. Improve community services and service provisions by generating knowledge regarding the needs of the bereaved, and implementing the findings in the delivery of palliative care services.

8. Provide opportunity to generate further research, theory, and hypotheses regarding the phenomenon studied.

Chapter Two:

LITERATURE REVIEW

2.1 CLASSIC THEORIES

Grief is a life altering and universal experience, one by which everyone will be effected. It is one of the few constants amongst all living existence. Artists, philosophers and scientists have explored grief for centuries, and it has been the subject of theory, debate, music, art and writing. Expressions are vastly individual, often influenced by culture and religious beliefs.

Literature throughout the ages explores grief, and “human concern for the dead predates written history” (DeSpelder & Strickland, 1999, p.42). Tributes to the dead date back to the Bronze Age (Walter, 1991). Philosophers as early as Socrates (399 – 470 BC) wrote on the subject of death. Theories about grief and bereavement, however, were not popularized until the nineteen hundreds, beginning with Freud (1917).

Freud was one of the first psychological theorists to explore the concepts of grief and bereavement in his classic work “Mourning and Melancholia”. His work has been described by Moules as “the genesis in the evolution of our current understanding of grief” (1998, p.5). The aim of the work was to achieve a better understanding of melancholia by comparing it with “the normal emotion of grief, and its expression in mourning” (Freud, 1917, p.152). Several authors have interpreted Freud’s work as indicating that to break the bond between the deceased and the griever, achieving attachment withdrawal, was the goal of grief (Lieck & Davidsen-Nielsen, 1991; Woof & Carter, 1996).

For Freud melancholia and mourning have certain characteristics or distinguishing features, which were recognised as a normal and expected process. He listed them as “a profoundly painful dejection, abrogation of interest in the outside world, loss of the capacity to love, inhibition of all feelings to a degree that finds utterance in self-reproaches and self-revelling and culminates in a delusional expectation of punishment” (1917, p.153).

Grief was further characterised by a preoccupation with the deceased where the mind must perform “the work of mourning”, (Freud, 1917, p.157). Mourning itself, according to Freud, was a non-pathological condition which normally reaches completion.

Although the same traits are met within mourning and melancholia, mourning does not experience the fall in self-esteem. Grief is performed on a conscious level, where the work of mourning absorbs the ego, resulting in loss of interest and inhibition (Freud, 1917). This is in contradiction to melancholia which is performed on an unconscious level.

Melancholia has three further conditioning factors identified by Freud (1917); “loss of the object, ambivalence, and regression of libido into the ego” (p.169). Loss of the object is characterised not only by a vast drop in self esteem, but of feelings of worthlessness, reproaching himself [sic] and expectations of being made outcast (Freud, 1917). Freud identifies melancholia as a depressive illness where the person suffering does not realize that there have been changes within (1917).

The melancholic’s behaviour is characterised by lack of shame and a loss of self-respect, coupled with constant taking of offence and feelings of being unjustly treated (Freud, 1917). The free libido, withdrawn into the ego, has not been

directed towards another object and in this way Freud feels, “the loss of the object became transformed into a loss in the ego” (1917, p.159).

In a later study by Abraham (1924), titled “ A short study of the development of the libido, viewed in the light of mental disorders”, several of Freud’s earlier ideas were modified, primarily that the “lower self esteem is not relegated exclusively to melancholia” (Hall, 1999, p.3), and that identification is not pathological but rather an aspect of normal mourning.

Abraham further extends ideas initiated by Freud’s 1917 work, discussing the temporary image of the object being transformed into elements in the life of the unconscious and thus the object being affected, resulting in feelings that the “ loved object is not gone, for now I carry it within myself and can never lose it” (Abraham, 1924, p437). Furthermore Abraham had a differing view from Freud on ambivalence, indicating it is not exclusive to pathological mourning or melancholia (Abraham, 1924).

Other theorists around this time, such as Deutsch (1932), began to study grief and depression. Deutsch, in her work “Absence of Grief” (1932), identified for the first time that complicated mourning is not necessarily the result of a manic-depressive condition, rather she argues that an adult who does not permit mourning to occur shows weakness in the ego. Such weakness is produced by two conditions; the first a defence mechanism to protect the ego from mourning and the second due to insufficient strength of the ego (Deutsch, 1932).

Klein focused her study on grief, titled “Mourning and its relation to Manic Depressive States” (1940), in the belief that adult mourning may be impaired by reviving difficulties which arose during childhood, particularly at weaning, where the child mourns the loss of the breast.

Lindemann wrote a landmark study in 1944 titled "Symptomatology and management of acute grief", which observed and interviewed one hundred and one patients who were experiencing grief, due primarily to the Cocoanut Grove Fire in Boston, or relatives of members of the armed forces. This pioneer study in grief investigation focused on acute grief being a "normal reaction to a distressing situation" (Lindemann, 1944, p141), rather than a psychiatric or medical condition.

Lindemann recognises five characteristics or components of bereavement reaction he felt were common; "The picture shown by persons in acute grief is remarkably uniform" (1944, p141). Firstly, waves of somatic distress or discomfort are experienced characterised by physical manifestations such as shortness of breath, tightness in chest, tendency to sigh, complaints about exhaustion and problems with the digestive systems. This component of bereavement is also expressed with sensorial alterations, or feelings of distance from others.

Another component of bereavement reaction which Lindemann felt was common included a preoccupation with the deceased's image. Guilty feelings and searching for negligence in one's own behaviour immediately before the time of death is common, as is a decrease in warmth and connection with others, not being bothered with friends or relatives. The fifth component of bereavement reaction which Lindemann discussed in his paper is characterized by an aimless, restlessness, continually searching for something, and a general loss of routine or patterns of conduct. He also adds a sixth characteristic expressed by people he labeled as showing pathological reactions; which consists of the bereaved displaying behavioural traits of the deceased, particularly those seen just prior to the time of the tragedy. Lindemann (1944) talked about people interviewed showing symptoms of the deceased's last illness and their mannerisms, such as walking like the deceased.

“Grief Work” is the title Lindemann (1944) gave the process a person goes through during the grief reaction. It consists of three phases, namely “emancipation from the bondage of the deceased, readjustment to the environment in which the deceased is missing, and the formation of new relationships” (Lindemann, 1944, p.143).

In the first stage of grief work the bereaved must relinquish the attachment he or she has to the deceased and develop a new relationship with the loved one based on the status which has been altered. Lindemann’s (1944) second stage of grief work involved readjustment to the world without the deceased, where the person must adopt new skills and roles to accommodate the world s/he lives in now without their loved one, and to compensate for functions once performed by the deceased. The final phase of Lindemann’s grief work is when the bereaved is able to invest emotional energy into someone or something else. Preoccupation with the deceased is lessened and there is a gradual re-entry into both new relationships and daily life in general.

Having identified the grieving process from his studies of the bereaved, Lindemann expands his work by identifying nine “morbid grief reactions (which) represent distortions of normal grief” (1944, p.144). These consist of a “delay of reaction” (1944, p.144) where reactions are postponed from weeks to years. The bereaved may show little or no reaction to the news of the death. A “distorted reaction” (1944, p.144) is typified by a period of time where the bereaved behaves normally, then after an interval they develop alterations or distortions in their behaviour. Thirdly Lindemann discussed the presentation of a group of medical diseases or psychosomatic conditions being the manifestation of morbid grief reactions. These predominantly include asthma, ulcerative colitis and rheumatoid arthritis.

On a social adjustment level Lindemann's 1944 study explores several abnormal grief reactions as effecting relationships, extending not just to irritability but social isolation and hostility, for example accusing doctors and surgeons of neglect.

Closely related to the above manifestation of morbid grief reaction is "lasting loss of patterns of social interaction" (1944, p.145) which Lindemann labels his seventh abnormal reaction. Here the patient is eager to be active but cannot initiate activity. In addition the person may be active to such an extent that the behaviour is detrimental, for example giving away belongings or making bad economic dealings (Lindemann, 1944)

The final morbid grief reaction listed in Lindemann's 1944 work is labelled "agitated depression" (p.146) and its manifestations are agitation, self-accusation, obvious need for punishment, tension and feelings of worthlessness; symptoms listed in earlier work by Freud (1917) when discussing characteristics of melancholia.

Lindemann's groundbreaking work also discussed certain indicated predictions of patients at risk to morbid grief reactions, useful for prognostic evaluation. He concludes his study with a discussion of the "proper psychiatric management of the grief reactions" (Lindemann, 1944, p.147). Here he recognized the importance of sharing the bereaved's grief work, and acknowledges the traditional role of assistance given by religious agencies. Vital to recovery was the patients need to "accept the pain of bereavement" (Lindemann, 1944, p.147), reviewing the previous and present bond with the deceased, and adjusting to his/her reactions. Furthermore s/he must work through feelings of hostility and fear of insanity, expressing the loss and verbalizing guilt feelings. New patterns of behaviour were likely to occur. According to Lindemann's work this can be assisted professionally "in eight to ten interviews" (1944, p.147) with the bereaved.

2.2 MODERN THEORIES

The 1950's and 1960's saw what is known as the emergence of the death and dying movement (Demi & Miles, 1979; Benoliel, 1997). One of the landmark theorists of the time was John Bowlby (1961, 1969, 1980). In the opinion of Stroebe and Schut, Bowlby's attachment theory is "the most impactful theory in the field of bereavement" (1995, p.3).

Bowlby's theory is based on attachment and loss, and written to "offer an alternative to the traditional metapsychology of psychoanalysis" (1982, p.668), and stemmed from the belief that bereavement is an unconscious process which pre-supposes childhood experiences of attachment are of great importance when experiencing later loss. His fundamental belief was that "responses to be seen in infants and young children to loss of mother are, at the descriptive level, substantially the same as those to be observed when the older child or adult loses a loved figure" (1961, p.22). Bowlby (1961) believed the processes underlying these responses are very similar.

Attachment behaviour has a function in survival and is goal directed, ensuring emotional and physical security. Bowlby (1961) explores this idea, and some common psychological expressions seen in mourning; particularly weeping and anger, which are almost universal and used as a way of finding the lost object. His work moves away from the more traditional studies of grief, where it is described as pathological.

In later writing attachment behaviour is defined by Bowlby (1982) as "any form of behaviour that results in a person attaining or maintaining proximity to some other clearly identified individual who is conceived as better able to cope with the world" (p.668), and is the basis of his work on bereavement, starting with his 1961 work titled "Processes of Mourning", followed by three volumes on

attachment and loss. These are titled “Attachment” (1969), “Separation – anxiety and anger” (1973), and “Loss- sadness and depression” (1980).

Mourning, according to Bowlby (1961), has normal processes that are intricately related, and he identifies seven of these main themes. He titles his first theme in question form, that being “What is the nature of the psychological process engaged in healthy mourning?” (Bowlby, 1961, p.318), under which he explores the effects of withdrawing emotional attachment from a lost object and preparing for developing new relationships.

Bowlby’s second theme and influential question explores why mourning is so painful. Thirdly Bowlby explores the relationship between mourning and anxiety, adopted from the view that anxiety is the response when the mother figure is temporarily absent, turning to mourning when she is permanently gone (Bowlby, 1961). This leads into his fourth theme, in which Bowlby questions the motivations of mourning. This complex theme explores the expressions of weeping as an instinctive behaviour, his beliefs of such being backed by the classic works of Darwin (1872) and Shand (1920).

Mourning associated with anger and hatred is of great concern to Bowlby (1961), anger with the lost love playing a vital role in unhealthy mourning, or pathological grief, but it is questionable whether or not it is a part of healthy mourning. This anger has two objectives; anger against anyone who seems to have contributed to, or been responsible for the loss, and secondly anger against those who are seen to impede the reunion with the lost object (Bowlby, 1961). This is Bowlby’s fifth theme.

Bowlby’s (1961) sixth theme explores the defining line between pathological and healthy mourning, a question of debate at the time, and still under debate at present. Bowlby here discusses several theorists’ opinions regarding the

distinction between healthy and pathological grief, citing from landmark works such as Freud (1917), Klein (1940), Lindemann (1944), and Engel (1961).

Discussion of normal versus pathological grief leads to Bowlby's raising of the seventh question or final theme "at what stage of development and by what processes does the individual arrive at a state which enables him [sic] thereafter to respond to loss in a healthy manner?" (1961, p.318). This is also the question of continued debate; when does the grieving person achieve closure, or when does the melancholia become mourning and visa-versa? Bowlby's theory follows the earlier ideas of Klein in the beliefs that such resolution depends greatly on childhood experiences and relationships.

Before discussion of his Phases of Mourning in his 1961 work, Bowlby emphasises primitive instincts that influence mourning through a variety of extensive studies of animal behaviours. Here he cites many examples of higher animals that show similar patterns of loss to those of humans.

Bowlby's theory, as written in 1961, contained Three Phases of Mourning. Later acknowledgments in his 1980 work was the discussion of the omission of an important, albeit brief, phase; the first phase of numbness (Bowlby, 1980). This is the phase where the bereaved is stunned, often denying the loss and not truly understanding it. The second phase is that of yearning and searching, or the "urge to recover (the) lost object" (1961, p.333). As the title suggests this phase is represented by behaviours that manifest the urge to find and reunite with the lost person. A preoccupation with the deceased can occur, both in actions and dreams, with actions indicating the lost person still present (Bowlby, 1961).

Two main features of Bowlby's second phase of mourning are weeping and anger. Man [sic], as well as many other creatures, cries as a first response when he misses his mother as an infant; "When the infant creature cries, his mother usually responds by returning to him" (1961, p.333). Thus this ancient instinctual

response is activated when grieving. Anger is another instinctual response to recover the lost love, and according to Bowlby there is a “sharp increase of aggressive behaviour which occurs in young children separated from their mother figure” (1961, p.333). It is proposed that these adaptive functions, such as aggression toward the loved object, are to prevent the separation occurring again. Thus hostility and anger towards carers is said to be due to the same motivation; that is not to be comforted, but to be reunited with the lost object (1961). Bowlby mentions several other behaviours seen in this second phase of mourning, including repeated disappointment, disbelief, irritability, accusation, tension and ingratitude.

Despair and disorganisation are the central theme to Bowlby’s third phase of mourning. Continued disappointments teach the bereaved that reunion with the lost object is not viable, and the behaviour shifts away from the lost object itself. Here “despair sets in and behaviour, lacking an object towards which to be organized, becomes disorganized” (1961, p334).

Apathy and a disregard for old patterns of behaviour and thinking is also seen in Bowlby’s third phase of mourning, along with lack of ability to see a future or meaning in life. This leads into the fourth and final phase where the bereaved breaks attachments with the lost object, redefining their sense of identity and situation, and beginning to establish new bonds, relationships and acquire new skills. Healthy links with the lost person can be identified and an effective loving relationship can be retained; one that is appropriate (Bowlby, 1961).

In conclusion, Bowlby’s theory of mourning expresses a pattern of behaviours which, although somewhat varied, are sequential and very influential on one’s life. He believes grieving is needed for healing and for moving into the future, making new bonds possible. Many of these behaviours or reactions are instinctive, their adult expressions reflecting patterns learned when suffering loss or separation as a child, and thought to be somewhat predictable (Bowlby, 1961).

Engel (1961) introduced the idea that the process of mourning and the process of healing are similar; grief being psychologically traumatic and a departure from health and well being. Worden (1987) describes Engel's work as "thought provoking" (p.9), describing the core as being "that the loss of a loved one

is psychologically traumatic to the same extent as being severely wounded or burned is physiologically traumatic" (Worden, 1987, p.9-10). He sees mourning in terms of healing over a course of time, the amount of impairment being a matter of degree.

In 1961 Engel described the normal sequence of grief in six stages, which can be interfered with by lack of coping resources, sub-optimal healing conditions and unsound intervention. His first stage of the healing process is shock and disbelief, where the mourner is stunned, thus blocks out the pain and reality of the loss and attempts to protect him/herself by being numb. When the reality of the death starts to become conscious, and the anguish of the loss starts to mean something, the mourner is in the second phase, which Engel titles developing awareness. Here the bereaved often feels anger, exhibits self-destructive, guilty and impulsive behaviour. Crying is also common. Engel (1961) sees crying as an important communication in asking society for support .

Restitution is the third phase in Engel's (1961) normal sequence of grief. It is a time where rituals, such as the funeral, help in the recovery process. This is done through recognizing the reality of the death, identification and expression of feelings, social supports and helping the bereaved cope. This leads into the fourth phase where the mourner attempts to deal with the loss, or the void. Preoccupation with the deceased, both in thought and conversation, often occurs. Most negative features of the deceased are extinguished from the mourner's mind. Any hostile or negative feelings towards the dead are

repressed, leading to Engel's fifth phase of normal grief; that of realization (1961).

In the fifth stage a sense of responsibility for the death and of the deceased often occur. This preoccupation gradually lessens, with an eventual decrease in sadness when remembering the deceased, and eventually an interest in new relationships begins, with movements being made towards the new life. According to Engel the outcome or sixth stage is complete when the bereaved can realistically remember both good and bad in the relationship with the deceased, which usually takes a year or more (1961).

Engel's 1961 work also identified five characteristics of grief. They are an interruption of the expected and automatic aspects of living, attempts to dispute and deny the death, expression of certain behaviours used to solicit help from others and express feelings, construction of a mental representation to replace the physical one lost, and personal experiences of grief which detaches the mourner from the deceased in order to rejoin him or her back into society.

Although, as already discussed, other theorists had introduced the idea of stages of grief (Bowlby, 1969; Engel 1961; Lindemann, 1944), the classic work of Elisabeth Kubler-Ross changed the way society viewed death and dying. DeSpelder and Strickland (1999) described her "famous five stages (as having) become almost modern mythology of how grieving should be done" (p.226). It is a theory not only used for the education of medical and nursing students, but is so commonly known it is popularised in modern day cartoons such as "Bloom County" (1985) and television shows such as "The Simpsons" (Groening, 1990).

Kubler-Ross' (1969) work outlined five stages, both identified in the grieving individual after the loss, and terminally ill patients facing their own death. She interviewed over two hundred dying patients in research for her book "On death and dying" (1969), which stimulated understanding of the dying process. She

includes many quotes and stories from her dying patients' interviews, both to teach and to emphasize her points, and thus has "directed caregivers and lay people alike to thoughtful consideration of issues relating to dying patients, as well as to the universal human confrontation with death" (DeSpelder & Strickland, 1999, p.157)

Kubler-Ross (1969) found that most react to the awareness of a terminal illness or bereavement "with the statement 'No, not me, it cannot be true'" (p.38). Thus the first stage of her theory is labelled denial and isolation. She defines denial as a "buffer after unexpected shocking news, and allows the patient to collect himself" (p.39). She considers it a natural, healthy reaction and coping mechanism to painful stimuli, and finds that most people will use this temporary defence. Denial is not only used initially but also throughout the process from time to time.

The second phase of Kubler-Ross' theory (1969) is the phase of anger. This is the phase where people ask 'Why me?' This phase is often difficult to cope with, especially for family and staff, as the anger is displaced and projected onto people and the environment. There are often problems with the caregivers, the staff and the hospital, and her study found that "nurses even more often (are) a target of their anger" (p.51). Anger is also a way for the patient to make sure s/he is not forgotten, (Kubler-Ross, 1969, p52), and thus it is important to give the respect and understanding, time and attention necessary to ensure the person still feels valued.

Kubler-Ross (1969) titles the third phase bargaining and it is the phase where individuals try to postpone the inevitable from happening by striking a deal or entering an agreement. The bargain, according to Kubler-Ross (1969) is usually always for an extension of life. Added to the bargaining is the finality of the promise; "it includes an implicit promise that the patient will not ask for more if this one postponement is granted" (1969,p84). The bargains are usually kept

secret and are often made with God. During this stage guilt is often noted, for example guilt for not attending church more regularly or for hostilities in life (Kubler-Ross, 1969).

The fourth stage is labelled depression, and in this stage Kubler-Ross (1969) discusses a period of time where the patient or the bereaved begins to lose the numbness, anger or stoicism, and feels great loss, often of several facets. The losses are not only physical, but also include financial, psychological, job or role losses, spiritual, and loss of independence.

A person who has worked through the previous four phases, having expressed his/her depression and anger, envy and guilt, and has mourned his/her losses should, according to Kubler-Ross (1969), come to the stage of acceptance. Expressions such as “giving up” (p.113) or “what’s the use” (p.113) are quotes from her interviews in her 1969 work, but an emphasis is placed on the fact that this stage is not about resignation or hopelessness, but about “the final rest before the long journey” (p.113). Kubler-Ross’ (1969) study showed that most people reached this stage of acceptance before death.

Kubler-Ross’ (1969) work goes on to discuss the role of what she labels ‘hope’, even in the most accepting and realistic of patients. Hope did not always mean a cure and miracles did not necessarily buy time or remission.

Kubler-Ross writes extensively about the significance of the patient’s family, the role they have in care, and the changes and grief they may experience. She encourages the expression of one’s grief and anger, and for carers and staff to be available; not necessarily to provide professional counselling, but to be there as “a human being, a friend” (p.180). Such a notion was rather revolutionary for its time and still held to be seen as such in many areas today.

Another theorist and clinician in the work of grief is Parkes. His work comes from a psychiatrist's point of view, indicating that, "part of the difficulty in fitting grief into existing descriptive disease categories derives from the fact that grief is a process and not a state" (1972, p.21). He has worked extensively with Bowlby and Weiss, and is an honorary consultant psychiatrist to St Christopher's Hospice in England. He has devoted his work to the study of mourning, and arguably his most well known work, a book printed first in 1972 titled "Bereavement: studies of grief in adult life", is based on twelve years research of the reaction of widows to loss. "Not only has Dr Parkes furthered our scientific understanding of grieving but he has played an active part in trying to develop means whereby bereaved people can be helped" (Bowlby, 1972, p.8).

Talking from a physiological viewpoint Parkes discusses the sympathetic and parasympathetic nervous systems and their influences on reactions, preparing the animal for action (1972). This is used to explain symptoms observed directly after loss. These symptoms include appetite and weight loss, headache, palpitations, anger, irritability, panic attacks, general aches and difficulties sleeping, very similar to symptoms of stress. Recognized by Parkes is the variety of factors which influence how a person will react to stress, not just the instinctual aspects. He lists them as characteristics of the stress, coping techniques, previous experience, ability to tolerate anxiety and maintain self-esteem (1972).

Parkes describes a distinct characteristic of grief as being pangs, episodes of pain and anxiety (1972). As time passes their frequency reduces, and tend only to occur when the loss is remembered, rather than occurring spontaneously and very frequently as Parkes feels they do at first. Anger is part of the alarm, and in Parkes' study this is characterized by dry mouth, feeling of panic, and other autonomic activity expressed earlier, added to difficulty in concentration, restlessness, deep sighing, loss of interest in the outside world, and pining. "Pining", according to Parkes, "is the subjective and emotional component of the

urge to search for a lost object” (p.58). Here one can see the parallels Parkes has with Bowlby’s theory; not surprising considering the work they did together. This searching is considered survival behaviour for individuals and species alike, in an effort to recover the lost object (1972).

When the most intense period of pining occurs, Parkes observed in his study that “‘something’ may happen to mitigate the pain of grief” (1972, p.77). This he describes as a change or misperception, be it only for a moment, which indicates the search is over and the lost person is close at hand. In his interviews with widows he found many comforted themselves with such an idea, believing their loved one could hear their prayers, are nearby to talk to, or placing something beside them at night in bed. The aim of this stage is to relieve the pining and restlessness, seeking comfort from these behaviours (1972).

In Parkes’ 1972 study he indicates that the above behaviour is instinctual for comfort or survival, citing studies of similar animal behaviour, and associating it with childhood behaviour in humans. During this stage Parkes observes the widows he interviewed talking of ‘seeing’ their husbands in the street, experiencing hypnagogic (half-waking) hallucinations where they see their loved one quite clearly, and having vivid dreams of their loved ones commonly coming back to life or saying goodbye (Parkes, 1972).

Lindemann (1960) described how the deceased’s image is lost from memory, however Parkes (1972) found the opposite to be true, finding that “ the image of the deceased was retained with great clarity” (p.89). In fact he found that the clarity of memory tends to increase in the first year of bereavement, unlike other features of grieving which tend to diminish as time passes. Frequently the memory, although clear, can become distorted, with negative images being forgotten and the positive images being idealized. This is encouraged by society (1972). Parkes describes the feelings of loss of purpose, the world being chaotic

and nonsensical, with energy being spent on finding what cannot be found therefore ignoring the possibilities of what can.

Another important aspect of loss and grief is anger and guilt, which Parkes explores in detail, as do many theorists and authors of grief literature (Lindemann, 1944; Bowlby, 1961; Kubler-Ross, 1969; Rando, 1984; Worden, 1987). Parkes feels that, as grief is not a state but a process, its expression changes with time. He found in his study of widows that most reported excessive anger during the first year of bereavement (1972), and found that anger should not be considered a continuous state. The most frequent form was irritability and bitterness, associated with feelings of insecurity, restlessness and tension. The anger was often directed at medical staff or God, as both were seen as having power over life and death. Parkes' study also concluded that those widows who expressed the most anger "became more socially isolated than those whose anger was less severe" (1972, p.105).

A final characteristic or theme of grief, which Parkes writes about, is the gaining of a new identity. This is not a new concept, as Parkes' review of the work of Freud, in discussing the psychoanalytic literature states "that the bereaved take into themselves certain aspects of the lost person" (Parkes, 1972, p.111). Several of the widows interviewed appeared to take on activities and characteristics derived from the deceased, influenced greatly by the new and often unexpected changes in role thrust upon them.

Included in Parkes' work is a description in detail of different aspects and areas of grief. His 1983 work with Weiss titled "Recovery from Bereavement", explores the three tasks which they believe make up the process of grief work, which must be completed in order to recover (Parkes & Weiss, 1983). Firstly the bereaved must develop explanations of the loss, answering questions and identifying causes of death. This period is characterized by searching for the deceased and

a “preoccupation with thoughts of the lost person” (1972, p.98), to enable the bereaved to relax their fear and anxiety of new loss.

The second task or component of grief work is the acceptance of the loss, which can only occur after repetitive facing of the loss. Such review occurs through feelings, thoughts, emotions and memories. “There is painful repetitious recollection of the loss experience, which is the equivalent of worry work and which must occur if the loss is not fully accepted as irrevocable” (Parkes, 1972, p.98). After this is done the grievers can reach a point where the reminders are no longer too painful and thus acceptance of the loss is achieved.

Finally a new identity is assumed; this is the third task which, according to Parkes (1972) and Parkes & Weiss (1983), needs to occur in order to recover from grief. Mourners become aware of discrepancies between the world that was and the one that now is and thus “develop new identities that reflect their new circumstances” (Rando, 1984, p.27). The mourner attempts to make sense of the loss and modify assumptions, the speed of progress of which is not important as long as such a process is occurring (Parkes, 1972).

Marris, in his 1958 work, studies seventy-two East London widows over a two year period. Later work in 1974 extended his theory, which sought to replace Bowlby's notions of attachment and instinct by structures of meaning. He feels that emotional attachment to others is represented by an internal schemata; and such defines involvement and interaction. Grieving, according to Marris, is a response to loss of meaning, and breaks the thread of our world, that of continuity (1974). It's characterizations are similar to other theorists previously reviewed, stating that the grieving widows clung to memories and possessions of the deceased, experienced anger and ill health, often talked to and felt the presence of the deceased, and found replacement of the deceased not readily acceptable; his figures (1958) of the rate of re-marriage being low.

Resolution of grief, according to Marris (1974) depends on the successful working through of two conflicting tendencies. Firstly a yearning for the deceased, reliving events or episodes, thoughts and even hallucinations being orientated towards the time before the death. The second is the tendency to deny the issue, forgetting or avoiding thoughts of the lost person and orientating thoughts towards the future. His work stresses the importance of rituals and mourning rites, allowing simultaneously a recovery and a time to allow the bereaved to occupy him/herself with the past and care for the deceased (1974).

Rando theorized a Six "R" Process of mourning. Her 1984 book called "Grief, Death and Dying: Clinical Intervention for Caregivers" further develops her conceptualisation under the subheading of psychological, social and physiological manifestations of grief. The Six "R" Process of mourning consisted of Recognizing the loss: phase one, where the grieving individual acknowledges, and understands the death. The second part of the process is to React to the separation, experiencing and expressing pain (Rando, 1984).

The third "R" in Rando's process of mourning is to Re-collect and Re-experience the relationship with the deceased and the deceased themselves, by realistically remembering and reviewing the person, and reviving the feelings surrounding this. Relinquishing the attachments to the deceased and the world and life they represent is the fourth part in Rando's process of mourning, followed by Re-adjustment. This fifth part of the process allows the bereaved to adapt and move on, whilst still remembering the old and forming new relationships with the deceased. Once these steps are worked through, the bereaved reaches the sixth and final "R" and is able to Re-invest (Rando, 1984).

Recognizing the importance of theories to acknowledge grief as an individual process, Rando revises her work, and the work of others, by fitting the psychological reactions to grief into three broad categories, that of Avoidance, Depression and Despair, and Reestablishment (1984). The first of these phases

Rando labels the “Avoidance Phase” (1984, p.29), characterized by shock, disbelief and denial. The individual is overwhelmed, and tries to deny acknowledgement of the loss. Numbness, confusion, and feelings of being dazed occur during this period. Disorganization and confusion are common.

“Confrontation, a highly emotional state wherein the grief is most intense and the psychological reactions to the loss are felt most acutely” (Rando, 1984, p28) is the second phase of normal grief. The shock has worn off and the loss is recognized. Emotions are extreme and the ability to express this causes conflict. Fear, anxiety, and a sense of panic are expressed, along with anger and guilt. Self hatred may be expressed, and often the anger is displaced. Depression and despair are also discussed, and restlessness, anxious wandering, and tension are common feelings, along with a pre-occupation with the deceased. This is often manifested in dreaming, reminiscing and thinking the person has been seen.

The Re-establishment Phase is the third and final phase, Rando (1984) describes in her manifestations of grief. As the name suggests this is the phase where emotional energy is re-invested into new ideas, things and persons, the mourner adjusts to the loss. Guilt is often present in the initial efforts of re-establishment, as the mourner may feel s/he is betraying the deceased by enjoying life without him/her. Rando explains the phase is not clear-cut, often co-existing with previous reactions (Rando, 1984).

Rando’s (1984) work also places a large emphasis on any factor, determinant or variable which “influences the grief reaction” (p.43), under sub-headings of psychological, social and physiological. Recognized here is the individuality of the process, yet proposing some predictable factors will occur (Rando, 1984).

Another well recognized grief theorist is Worden, whose theory comprised of “Four Tasks of Mourning” (1987, p.11), rather than stages. According to Worden,

mourning is a long-term process, and is completed when one can think of the deceased without pain or experiencing the physical manifestations of such, and when one can re-invest emotional attachment with those still alive.

Worden sees mourning as a necessary process, discussing in detail in his 1987 book "Grief Counselling and Grief Therapy" the manifestations of normal grief under sub-headings of feelings, physical sensations, cognitions and behaviours. His work also discusses in depth what he identifies as the determinants of grief, predictions of response to loss. He groups them into six categories; who the person was, the nature of the attachment (its strength, security, and presence of ambivalence), mode of death, historical antecedents (coping patterns for previous deaths), personality variables and social variables. Woof and Carter (1997) describe Worden's work as being the text of "dominance" (p.511) when referring to the concept of grief work, finding it "most influential" (p.511).

The first task of mourning identified by Worden (1987) in his theory is to "accept the reality of the death" (p.11). This task recognizes the reaction of denial. Another form of this is to place less significance on the relationship of the loss. Worden emphasizes that it is normal to hope for a re-union or deny the finality of the death, however for most people this is a short phase (1987).

"To experience the pain of grief" (1987, p13) is Worden's second task of mourning. Physical, emotional and behavioural pain is included here when discussing loss, and working through this phase is necessary, so as to avoid the grief manifesting in symptoms or behaviours. In describing this phase Worden explores the idea of society not being comfortable with the expression of feelings, therefore others may indicate to the mourner the subtle message that "you don't need to grieve" (1987, p.13), thus making completion more difficult. The importance of feeling the pain is emphasized along with the idea that with time it will pass (Worden, 1987).

Task three of Worden's theory of mourning is "to adjust to an environment in which the deceased is missing" (1987, p.14), which depends on the relationship with the deceased and the roles s/he played. Often the partner must take on roles previously performed by the deceased, requiring re-adjustment and new skill development. The final task is "to withdraw emotional energy and re-invest it in another relationship" (Worden, 1987,p.15), however this is not to "dishonour the memory of the deceased"(p.15), which is a common misunderstanding of his theory. Such conflict makes the completion of task four difficult but by coming to terms with emotional withdrawal and reinvestment one can complete the tasks of mourning. Worden emphasizes the importance of completing all tasks, not necessarily in any specific order, as "uncompleted grief tasks can impair further growth and development" (p.10).

One of Australia's most well known writers of grief literature, his work stemming from professional experience in the area of bereavement, is McKissock. In 1989 his book 'Coping with Grief' was published through the Australian Broadcasting Commission, following a program on ABC radio. His work expresses the opinion that grief is universal, the response to death being "the most significant, maybe because of its finality, maybe because death confronts one's own mortality or finiteness" (McKissock, 1989, p.7).

Although McKissock acknowledges the importance of grief being an individual process, and encourages its expression to be allowed and not smothered by society, he gives a guide entitled 'What is normal grief?' (1989, p.10), which outlines significant time factors and their relevant stage of grief. 'The first day' (p.10) the bereaved is expected to experience numbness and shock. As with many of the modern theories previously discussed, this is a time of denial.

On "the third day...reality is beginning to sink in" (McKissock, 1989, p.11), where numbness is wearing off and the pain and anxiety about coping and getting through the funeral is increasing. 'The Seventh day', according to McKissock

(1989), is characterized by isolation, loneliness and despair when friends and relatives depart, less people are visiting and there is an increasing awareness of reality. At four to six weeks McKissock finds people express to him that they are “getting worse...I'm going downhill” (p.12), or are seeking help for others who appear not to be coping. At such a time he counsels that the pain and despair are not necessarily worsening but defence mechanisms are wearing off, thus feelings are surfacing and he encourages finding someone to listen and allow expression of feelings, often repetitively.

McKissock's (1989) work acknowledges the significance of anniversaries and special dates as times, which may often be intensely painful with the grief of the first year waning in degrees of intensity. Physical reactions to grief, especially concerning lack of appetite and sleep disturbance, are discussed as normal, as are the stages or feelings of anger, guilt, depression, despair and replacement.

McKissock (1989) acknowledges the importance of allowing people permission to grieve and let them share their story, and emphasizes the importance of a good diet, keeping a diary, and seeking counselling. He states that research shows the bereaved without support have a sickness rate ten times that of non-bereaved, as well as a higher mortality rate (McKissock, 1989).

McKissock (1989) gives six basic principles which he feels are important to be adhered to which will “lead to the healthy resolution of grief and eventually enable the bereaved to heal” (1989, p.9). Firstly it is healthy and normal to express emotions and pain of loss, and secondly the grieving process is important “to healing the wound of separation” (1989, p.9). His third basic principle recognizes a wide range of feelings the bereaved may have from anger, sadness and shock through to hope, relief and acceptance. “The painful feelings will diminish with time” (McKissock, 1989, p.9) is McKissock's fourth principle, where he recommends seeking professional help if such feelings remain intense, and furthermore recommends seeking help if there is no expression of grief.

Lastly he indicates that people who do not successfully grieve are more likely to experience both physical and psychological illness (McKissock, 1989).

2.3 REVIEW OF CLASSIC AND MODERN THEORIES

Both the traditional and the modern theorists who have explored grief and bereavement have a large influence on how our Western society perceives it, and how we teach counsellors, nurses and other in the medical field how to deal with grief. “Nursing research has been built mainly on these earlier conceptualisations about grief” (Demi & Miles, 1979, p.107). Earlier models, particularly stage theory models, have come under criticism in the last few decades, particularly in the light of the emerging paradigm to be discussed further on in this work (see page 31).

Although the criticism is seemingly very relevant and appropriate, the literature and indeed this research does not propose to abandon the knowledge which has been gained from earlier studies and writings. Likewise, with regard to this work, the author recognises the vast body of knowledge gained by research and theory as essential.

When critiquing earlier models and research, it is documented that there is an absence of sound evidence upon which to base the theories (Strobe & Schut, 1995, Lev & McCorkle, 1998). Some earlier studies were based upon women only, dealt with sudden deaths, and “depended on subjects’ recall of an extremely difficult time” (Lev & McCorkle, 1998, p.146). Wortman, Silver and Kessler further this argument by stating that such models are “difficult to test or disconfirm empirically” (1993, p.351), and have a lack of application across cultures and societies (Strobe & Schut, 1995).

Stage models have a tendency to suggest to the bereaved how they should respond to loss, and what they should feel when grieving. They do not account for diversity of individual expression, recommending people to act in a certain way for a certain time, thus causing concern to the bereaved if they do not (Osterweis, Soloman & Green, 1984; Carter, 1989; Wortman & Silver, 1989; Wortman et al, 1993; Woof & Carter, 1997).

Others argue that such literal interpretation of the stage theories occur by inexperienced practitioners, who take the stages too sequentially (Rando, 1984, Worden, 1987), and try “to fit the individual to the theory” (Rando, 1984, p28-9). The stages may thus be useful in a descriptive sense. However if misinterpretation occurs, some fault could lie with the theorist’s explanation, as clinicians “distort the understanding of observers” (Moules, 1998, p3).

The labelling which occurs in stage theories leads to assumptions and prejudices. There is great power in labels and names. Using labels as Kubler-Ross (1969) does, for example denial, suggests abnormal behaviour, and is “laden with implications of abnormality, failure and dysfunction” (Moules, 1998, p4). Furthermore, the use of stages implies that grief is a passive process, one which ‘happens to the bereaved’ with implications of no control. Such an idea is challenged by both Attig (1991, 1996) and Moules (1998), and is explored in greater depth further in this study (see page 31).

Because of a lack of demarcation between stages and boundaries and a tendency to move back and forth between each, the idea that grief is sequential is questionable. “Bereavement reactions may ebb and flow as opposed to following the clearly demarcated steps proposed in the ‘staged’ model of bereavement” (Trunnell, Caserta & White, 1992, p279). If grief is systemized and defined too much it risks losing the nature of the complicated emotional process, which it is. (Leick & Davidsen-Nielsen, 1991). This creates a psychological description rather than a holistic one, rejecting the uniqueness of the process and

neglecting domains, such as the social, physical, cultural and spiritual. An expectation of closure is often evident with stage model theories and when this is not achieved a sense of incompetence and failure may occur. This issue is explored further under the 'New Wave Theories' heading below.

2.4 NEW WAVE THEORIES

In the last few decades a new paradigm has emerged which changes the focus of 'grief work'. The new mode has the potential to change not only its process, but its purpose and outcomes. Such theories and models may come to influence not only how carers and counsellors work with the bereaved, but also how society in general perceives grief. In turn, this new wave of thinking has the possibility of influencing cultural expectations regarding grief, as well as initiate further research in the field.

New theorists and writers, whose work will be examined in this section, have several key elements in common. The first and most influential is their underlying belief that survivors are 'allowed', and in fact encouraged, to maintain a continuing bond with the deceased. Modern and traditional theorists have labeled such responses as unhealthy, pathological or considered as complicated mourning (Freud, 1917; Bowlby, 1961; Parkes, 1972; Rando, 1984; Worden, 1987)

Several prominent theories discussed have advocated the idea that the aim of grieving is to sever the bonds with the deceased, (Freud, 1917; Bowlby, 1971; Parkes, 1972), in order to reach what they have labelled closure or completion of the grief process. Such assumptions depend on the basic idea that grief is "a finite, time limited and predictable process", (Moules, 1998, p.1), summarized well by Walter (1996) when he states that the "*purpose* of grief is, the reconstitution of an autonomous individual who can in large measure leave the

deceased behind and form new attachments. The *process...is the working through and resolution of feelings*" (p.7).

Theorists of this new wave of thinking reject these elements of classic text or clinical lore, the purpose now being the construction of a meaningful and healing relationship with the deceased which "enables the living to integrate the memory of the dead into their ongoing lives" (Walter, 1996, p.7). The process of this varies with each theory, and as new ideas evolve. Western Society's assumptions about grieving are often discussed and research cited to disprove such ideas, and the writers not only give reasons as to the advantages to maintaining a bond with the deceased, but also provide models and strategies on how this can be achieved.

To begin discussion on individual theorists in this chapter, it is important to discuss the work of Worden. As mentioned in the section 'Modern Theories' (see page 14), Worden's work (1987) is reviewed and the final task of mourning, so as to avoid impairment of growth and development, is "to withdraw emotional energy and reinvest it in another relationship" (p.15). The idea of such emotional withdrawal and reinvestment was changed by Worden in later editions of his work. Recently he acknowledges that the task is not to relinquish the relationship with the dead, but to relocate it; therefore agreeing with the idea that it is appropriate to maintain the bond with loved ones. Walter sees such a shift as "small but significant" (1996, p.12) as an "effect of the revolution" (1996, p.12), that is the new paradigm.

Other theorists who have furthered this new wave of thinking include Wolfgang and Margaret Stroebe, who have written and edited several texts on bereavement and grief, including "Bereavement and Health" (1987). Margaret Stroebe, in conjunction with Schut, proposed a new theory and model to deal with what they considered shortfalls in traditional theories in bereavement strategies. Their criticisms included "imprecise definition, failure to represent

dynamic processing that is characteristic of grieving, lack of empirical evidence and validation across cultures and historical periods, and a limited focus on intrapersonal processes and on health outcomes” (1995, p.2).

The model that Stroebe and Schut proposed is called the Dual Process Model of coping with bereavement, based on the idea of “The Grief Work Hypothesis” (Stroebe, 1992). This explores the belief that one must confront the bereavement in order to experience coming to terms with the loss and avoid ill health due to grief.

Stroebe and Schut (1995) identify two fundamental stressors; loss-orientated stressors and restoration-orientated stressors. Loss-orientation refers to the “concentration on, dealing with, processing of some aspect of the loss experience itself, most particularly, with respect to the deceased person” (1995, p.20). The focus is on the bond shared, expressed by rumination about the life together, the person, and the circumstances of the death. Loss orientation dominates early bereavement, however the authors point out that their model is “not a phasal model, we do not propose a sequence of stages, but rather a waxing and waning, an ongoing flexibility, over time.” (Stroebe & Schut, 1995, p.21).

Restoration-orientation is the label Stroebe and Schut (1995) gave the second type of bereavement stressor. They claim this is a relatively new concept in grief literature and counselling programming. It is not referring to an outcome variable but a second source of stress, focusing on “what needs to be dealt with (for example social loneliness), and how it is dealt with (e.g. by avoiding solitariness)” (Stroebe and Schut, 1995, p.21); not the result of the stress. This concept is referring to secondary stressors caused by the loss, such as role changes and task mastery, developing a new identity, and changes of identity and relationships in society.

This Dual Process model advocates oscillation, a dynamic process fundamental for successful coping, or the switching between loss-orientation and restoration - orientation coping. The authors feel this is a necessary defence mechanism that at times confronts the stressors of bereavement, and at other times allows avoidance. Stroebe and Schut (1995) emphasize that such oscillation is necessary for optimal adjustment, mental and physical health. They suggest this model is neither gender specific or culturally exclusive. Stroebe and Schut conclude from their theory that “confrontation with the reality of loss is the essence of adaptive grieving” (1995, p.28). The bereaved must both mourn the loss and adapt to new situations. This is a move to postmodern thinking that loss, as an individualized process, cannot be managed by counsellors as predictable.

Two of the first theorists to explore the new paradigm in depth were Wortman and Silver, who reviewed empirical research data which questioned and opposed several assumptions about loss and grief. Their 1980 work titled 'Coping with undesirable life events', and their 1987 work 'Coping with irrevocable loss' explore the idea that assumptions are derived from three main areas; firstly, from prominent theorists in the area, secondly, from clinical practice or clinical lore and thirdly, from society's cultural understanding of grief. Their work is based on the idea that “people hold strong assumptions about how others should respond to such losses” (1989, p.349).

Wortman and Silver's 1989 work explores five major assumptions about coping with irrevocable loss, describing the theorists who support these ideas, and then extensively review empirical data, which negates or questions such assumptions. They question the idea that when major loss occurs, “the normal way to react is with intense distress or depression” (p.350), quoting several classic theorists including Freud (1917) and Bowlby (1980), and modern works such as that of Osterweis, Solomon, and Green (1984), who state such a reaction is near universal. However when Wortman and Silver studied empirical evidence which “included a more systematic and rigorous assessment of depression or distress,

it is clear that such a reaction is by no means universal" (1989, p.350). They cited five research studies which assessed depression by using strict diagnostic criteria and found 22.7% or less of their respondents could be classified as depressed (Wortman & Silver, 1989).

Other four assumptions widely held by both theorists and society were scrutinized in Wortman and Silvers 1989 work. The assumptions analysed were; "distress is necessary, and failure to experience distress is indicative of pathology" (p.350), "the importance of working through the loss" (Wortman and Silvers, p.351), "the expectation of recovery" (p.352), and the assumption of "reaching a state of resolution" (p.353). Such findings have great influence on theory, research and intervention. Wortman and Silver (1989) conclude that alternative patterns of grief are a reality, the results showing that some people do go through expected patterns, however others appear to show no intense distress, or in fact show intense distress for a long period of time.

If society and health professionals continue to perpetuate unrealistic assumptions of the grief process, as discussed in Wortman and Silver's 1989 work, a bias can be placed upon the support needs of the bereaved, forcing alterations in behaviour, hopes and plans. It may also exacerbate feelings of distress among the bereaved, leading to the idea that their own behaviours are inappropriate or abnormal (Wortman and Silver, 1989).

Walter (1996) also rejects the dominant model found in bereavement literature, and offers an alternative sociological one. He proposes the idea that the bereaved wish to talk about the loved one they have lost with others who knew the person, constructing a biography to integrate the dead into their lives. This process "is principally conversation with others who knew the deceased" (Walter, 1996, p.7). The data gathered is primarily biographical, prompted by personal experience, which does not fit into conventional theories. Walter writes that the

biographical methodology is appropriate and his model “sees bereavement as part of how individuals construct their biography” (Walter, 1996, p.9).

The development of this paradigm, according to Walter (1996), includes two areas of revolutionaries who are advancing the thinking of grief work. The first are those grieving loss, and the second are the academics who were finding conventional wisdom no longer appropriate. In his exploration of the process of grief he encourages the bereaved to talk about the dead with people who knew them, as it gives them a deeper insight and understanding of their lives, an accurate picture of the deceased, and a means by which the author could “clarify thoughts, deal with unfinished business and prepare for the future” (Walter, 1996, p.13).

Walter (1996) suggests there are several reasons why the bereaved might not be able to talk to others who knew the deceased. Firstly he explains that, especially after sudden death, professionals such as doctors and coroners are too busy to explain the details of death, thus making it difficult to explore later for the family and friends. Secondly communication may be difficult as the expression of religious rituals may also prevent discussion, especially if the person is uncertain of appropriate behaviour. The bereaved may know the person in very different areas of life, such as home, work or sporting arena, thus talk becomes difficult away from what may be deemed the appropriate setting. Finally, geographical mobility and physical separation makes social contact difficult. Longevity can add to this problem.

Walter's 1996 work encourages researchers to test the model he has proposed, which could “supplement, rather than replace, the conventional wisdom” (p.20). If it proves to be appropriate it would have major implications in the way the bereaved are counselled, the support offered, and how ceremonies and rituals, such as funerals, are approached.

An alternative perspective, yet still within the ideology of the new wave paradigm, is Attig's work which questions traditional theories of grief and bereavement, stating "death does not end our caring or our loving but is compatible with our continuing and transforming our care and our love" (1996, p.170). He questions the idea that grief is a passive process, something which happens to the bereaved, and instead he promotes the process as active. This is the central theme to his 1991 work, which rejects stage phase and medical treatments of bereavement and discusses "grief as an emotion, and grieving as a coping process" (p.387). Although the events which caused grief are not chosen, the grieving experience has many choices. According to Attig the bereaved can "choose whether to indulge in the paralysing grief emotion...or struggle against what tempts them in it" (p.390-1).

If the bereaved perceive grief as an active process, as discussed by Attig, they can encompass the more complex aspects of bereavement, self-understanding is promoted, and better direction is given for the carers of the bereaved. This leads to successful grieving which enables the bereaved to "cherish the memory rather than be overwhelmed by it" (p.392). Active grief provides the bereaved with their own pace, style and focus of attention. By incorporating the deceased and what they cared about in their daily lives, the bereaved "re-interpret several aspects of (their) experiences as survivors" (p.187), finding a way to love the deceased without their physical presence, helping this pain to carry less of a pervasive aspect in their lives (Attig, 1996).

The deceased lose "the continuing presence" (Attig, 1996, p.171), the security, and the cohesiveness. However what the bereaved do not lose is the meanings the person brought, the inspirations and affects, and the influences that the deceased can continue to have. They "do not lose any of the time lived with the deceased prior to death" (Attig, 1996, p.171). The bereaved continues to love the deceased, not as a fixed memory but as someone who has the power to move and motivate them. The ways he proposes the bereaved achieve this is by

retelling and reviewing the stories shared, constantly re-interpreting the value and meaning they give.

Attig develops the idea of relearning the relationship with the deceased by respecting individuality, as no two relationships are the same. The bereaved lives' take distinct courses and find a unique place of understanding (Attig, 1996). Understanding what one has and has not lost helps motivate the bereaved to address their helplessness, another advantage Attig sees as essential to developing a relationship with the deceased, with the hope that this will provide caregivers' guidance. Caregivers, by understanding the importance of this relationship, can listen, comfort, and support without encouraging the bereaved to let go of the dead, as has been encouraged in other theories (Attig, 1996).

The theme of continued relationship, rather than disengagement from the deceased, is expanded in a book titled "Continuing Bonds" edited by Klass, Silverman and Nickman (1996). This book addresses not only the main ideas generated within this new paradigm, but reviews cultural influences, romantic, modern and post modern ideas regarding the grief process and examined extensively the literature regarding the benefits, or in fact the necessity, of continuing a relationship with the deceased. The book's aim is to "expand understanding of the bereavement process, which (the authors) see as a dynamic part of human life that has no real end" (Silverman and Nickman, 1996, p.349).

In Western Culture in the 19th Century, a time referred to as the Romantic Age, love is placed as a central concept of human endeavour. Thus, as Stroebe, Gergen, Gergen, and Stroebe (1996) discuss, Western Culture of only one hundred years ago viewed death very differently to today's society. The idea of dissolving bonds would indicate a superficial relationship, furthermore devaluing the bereaved's profundity and self worth (Stroebe, Gergan, Gergan, & Stroebe, 1996).

This issue of closure is a phenomenon found in the literature of the twentieth century, beginning with Freud's 1917 work 'Mourning and Melancholia'. It is the modernist view, one that promotes "goal directedness, efficiency, and rationality" (Stroebe et. al. 1996, p32). However research into grief in other cultures, particularly non-Western Cultures, reveals a great variety of beliefs. Research has revealed sharp contrasts with Western ideas, whereby the continued bond with the deceased is encouraged and expected both in Buddhist and Shinto religions (Yamamoto, Okonoji, Iwasaki and Yoshimura, 1969; Yamamoto, 1970). The Hopi of Arizona, a native American tribe, however promote the breaking of the bond with the deceased and forgetting them as soon as possible. This follows the belief that contact with death is dangerous as the spirit of the dead is a depersonalised entity which brings pollution, thus although they may feel pain, the bereaved "give themselves over to no overt transport of grief" (Mandelbaum, 1959, p.201).

Klass, Silverman and Nickman (1996) suggest grief is an individual process, with diverse groups engaging in varying patterns of grief. Research and therapeutic outcome from this postmodernist perspective can therefore "only be made from within the same cultural framework" (1996,p.41) within practices that are culturally embedded.

In the conclusion of their book 'Continuing Bonds' Silverman and Nickman emphasize that although they propose a model of grief which encourages and values a bond with the deceased, they do not suggest one should live in the past, realizing the "paradox of letting go and remaining involved" (1996, p.351). The bond, they say, will shift and change with the time, having new importance. The connection remains present. It will be influenced by rituals, family and society. The authors are reluctant to define new categories of pathological grief as the old model did, thus "allowing individuals room to make their own meaning and their own peace" (p.353). It is hoped such views will have a positive influence on

therapeutic intervention, providing a new perspective on grief. They hope to bring conversations about death into living, and stimulate new development of a possible model of resolution of grief, which will emphasise the importance of human connection, both dead and living.

Moules joins a small but growing list of authors who propose that grief is not “a finite, time limited, and predictable process “(1998, p.1) allowing the bereaved to find a way to incorporate loss in their everyday lives. Her 1998 work, titled “Legitimising grief: challenging beliefs that constrain”, furthers the idea that not only are the traditional models inappropriate in modern Western society, but they increase suffering for the bereaved, labelling them as pathological and as failures. The power and problems associated with labelling are explored, as are the difficulties and problems of earlier stage theories.

Grief reviewed in reference to a proactive model of advanced family systems nursing practice was created by Wright, Watson and Bell (1996). Such a model is centred around the idea that people and their families have both beliefs that are helpful and ones which are constraining, which influence all aspects of healing. Thus “beliefs, stories and illness are intricately intertwined “ (Wright, Watson, & Bell, 1996, p.22).

Moules defines grief as a “journey of relationship...that searches for meaning and searches for a place in the lives and relationships that it touches” (1998,p.20). She offers a practical theory to assist the bereaved to find a place for the grief in their lives, avoiding the clouding and suffering which society, culture, gender and histories can generate.

The final author to be reviewed under the new paradigm, or new wave theories category is Vickio. His 1999 paper has a premise “that it can be adaptive to maintain bonds with loved ones who have died” (p.161). A review of contemporary Western views and of modernist theory is given, and his findings

are compared with Silverman and Nickman (1996), with 19th Century Western Culture and cross-cultural studies. Furthermore he explores this ideal of continued relationship in its role in modern film, sighting examples from modern films which encourage the continuing of a relationship after death (Vickio, 1999).

However the emphasis of Vickio's work is on strategies of maintaining connectedness. His work proposes five approaches to "delineate methods for connecting with the deceased" (1999, p.165). Firstly 'The Life Imprint Concept' is discussed, an idea that the deceased has deeply influenced the survivors s/he knew well, in ways of beliefs, feelings, actions, attitudes and mannerisms. The second concept, to maintain a bond with the deceased, is by allowing that person's "life purpose into the fabric of our lives" (Vickio, 1999, p.166), consciously choosing the imprint they have on the bereaved's being. This is done by holding special significance to similar activities that they enjoyed together. Recognized here is the ability of such efforts to be maladaptive if one's personal goals and direction are discarded. Growth and enrichment can occur, as can inspiration from the dead, as long as it is contained within perspective. Possessions, creations and experiences shared can be given higher importance after the death. Such items as photos and videotapes form a powerful link with the deceased. This approach Vickio labels "The role of symbolic representations" (Vickio, 1999, p.167). Fourthly he recognizes ceremonial opportunities as vital to continue the relationship, involving the deceased in momentous and special occasions in very individual ways. Finally in order to continue and develop the growth in relationship with the deceased Vickio emphasizes the importance of reviewing the life story, with all its in-depth, meaningful and complex messages.

Vickio concludes his work with an important discussion of the implications these ideas have on counselling and outreach. Through his own counselling experience he has found that his clients have benefited and been empowered by the discovery that grief doesn't mean letting go. However he emphasizes such a

concept needs to be introduced at the right time and that it may cause some conflicting feelings. The nature of the bond must also be considered, and pressuring clients to actually maintain this bond should be avoided, thus respecting the individuality of each person's grieving process.

2.5 REVIEW OF NEW WAVE THEORY

The work of the authors in the new paradigm offers much to compliment, rather than fully replace, the ideas of stage theories. Each of the new wave theorists denotes time to analysing and criticising the classic theories, stating clearly their reasons for proposing new ideas (Wortman & Silver, 1989; Stroebe & Schut, 1995; Moules, 1998). However, this emerging work must be recognised as complimentary to a degree only, as in many areas it has the potential to replace earlier thinking, yet will not, and does not propose, to disregard the work and empirical studies performed from a modernist perspective.

Several of the models proposed under the new wave title are particularly subjective and individualistic in nature (Walter, 1996; Attig, 1996), thus making it difficult to obtain sound evidence to prove creditability. Lack of testability due to the unique nature, as well as the relative newness of these concepts influences the absence of sound or empirical evidence. At this stage there is not a large body of data collected to add to the knowledge base. The concepts leave few guidelines or handles on which to base practice, potentially making the work of counsellors difficult. Although some of the authors' explored relevant literature and theory when discussing developing ideas (Wortman & Silver, 1989; Stroebe & Schut, 1995), most of the works are written from the author's personal or professional experience (Walter, 1996; Moules, 1998).

Several writers acknowledge the need for further research and testing (Stroebe & Schut, 1995; Klass, Silverman & Nickson, 1996), but do not provide extensive

analysis. Wortman and Silver explored empirical data in the most detail, citing studies that are both extensive and longitudinal in nature, offering credibility and validity to their work (1989).

Comprehensibility of Stroebe and Schut's (1995) model may be criticised, because language use for major themes has the potential to cause difficulties at grass root levels. This model needs to be tested and explored further, with possible adaptations being made.

Thus one of the major difficulties facing the success of this emerging paradigm is its ability to be adopted by theorists, clinicians and society. Although this is recognised (Wortman & Silver, 1989), the actual methods to challenge and change present thinking are yet to be devised and proven.

Due to the nature of the new mode developing, there is a growing recognition of the need for original expression of grief by individuals (Walter, 1996; Moules, 1998), and thus a hesitancy to define complicated grief (Klass, Silverman & Nickson, 1996). Lack of boundaries offer great flexibility in grief behaviour, however, it must be recognised that without such guidelines, agencies must depend upon the subjective judgement of staff experience, with the possibility of harmful behaviour exhibited by the bereaved being considered acceptable. This is not to suggest such work should fall into the trap, as earlier theorists did, of strictly defining 'pathological' behaviours, thoughts, and feelings. Nevertheless, to be credible this developing paradigm needs to explore loose boundaries or concepts of healthy and unhealthy grieving patterns.

In these early stages it is unclear which directions this new model will take. There is an emphasis placed upon further discussion and development of ideas, along with exploration of models to implement the work. Although limited, this groundbreaking work offers a potential catalyst for future development.

2.6 ILLUSTRATIONS OF GRIEF

Several themes were dominant in the literature on grief. The reoccurrence of these prompted them in this literature review with the belief that it will add to the clarity of the work and to the reader's depth of understanding of the topic. The first theme reviews the variety of ways societies have chosen to express grief, followed by an exploration of the influences culture has had on grieving and the bereaved. The importance of grief as an individual process, the need to express ones own story, and the reactions and determinants of grief, including risk and resilience factors, have been explored.

"For generations, scientists and artists alike have attempted to describe the emotions of grief" (Woof and Carter, 1997, p.443). Expressions of grief are seen in many forms and via a variety of media, used both for artistic expression and grief therapy. The significance and meaning of death, loss and mourning are explored, relating both to society's view and those of the individual (Leick & Davidsen-Neilson, 1991; Benoliel, 1997; DeSpelder & Strickland, 1999). Furthermore, these expressions of the emotions of grief and the depiction of grief itself, influence society and individual views.

One way in which expressions of grief influence our views is by its depiction in the mass media. As DeSpelder & Strickland state " our attitudes towards death and dying are greatly influenced by the vicarious experiences offered by the mass media" (1999, p.18). News of terrorism, disaster, starvation and war produce huge audiences for the media, especially with modern modes of communication through not only film, television and radio but also via computer technology and the internet. This is a way we can explore meaning of death and elements of human nature (DeSpelder & Strickland, 1999).

All kinds of music, from gospel, popular, folk, rap and classical, express and explore themes of death and mourning (DeSpelder & Strickland, 1999). The themes range from requiem mass to popular songs expressing emotions felt after a friend's suicide. These messages influence the attitudes, not only of individuals, but cultures and society. Thus they are a most important and influential form of information regarding expressions of grief. A recent example of this is Elton John and Bernie Tauplin's 1997 version of 'Candle in the Wind', revised for and performed at the funeral of Princess Diana. This song is the biggest selling single world wide to date, with one million copies sold in just thirty-seven days (DeSpelder & Strickland, 1999).

Music thus can also be utilised as an important medium in grief work, with people finding "great pleasure in music that calls forth strong and good memories" (Leick & Davidsen-Neilsen, 1991, p.52). Music therapists are being incorporated in palliative care teams, using music not only for symptomatic control but also for the dying and their families to express their feelings and emotions regarding death and bereavement (Porchet-Munro, 1993; Hogan, 1998,1999).

Literature is another powerful medium, used over the centuries of recorded history to document and explore death and mourning. Such expressions are found in poetry, stories, teachings and essays, including classic literature from Homer's 'Iliad' (1950) to Shakespeare's 'King Lear' (1952). Poems such as Auden's 'Funeral Blues'(1936) were popularised through another medium, that of the film 'Four weddings and a Funeral' (1993).

Other well-known example of grief expression in literature include 'The Diary of Anne Frank' (1954), Allen Ginsberg's 'Kaddish' (1961), Elie Wiesel's 'Night' (1969), Sogyal Rinpoche's 'Tibetan book of Living and Dying' (1972), and C.S. Lewis' autobiographical account 'A grief observed' (1961). All of these works explore attitudes of death and grief from very different perspectives, yet all help to formulate ideas and express emotions of grief.

Not surprisingly literature and writing is encouraged to be used as a form of therapy. For Leick and Davidsen-Nielsen their experience in grief therapy shows “the great majority of people find that writing letters to the person they have lost is a strong and meaningful experience” (1991, p.52). Use of writing in grief therapy not only helps to bring out and express the emotions of grief, venting feelings of love and anger, but also helps to separate and differentiate feelings (Leick & Davidsen-Nielsen, 1991).

Across the centuries the visual arts have depicted different elements of death, including painting, sculpture, images and film (Pacholski, 1986; Benoliel, 1997; DeSpelder & Strickland, 1999). This covers an extensive spectrum, ranging from the personal loss of a child to society’s political views on war. These expressions are often closely tied with religion and culture, for example the multiple depictions of Christ’s crucifixion. Dating earlier still in ancient Egypt are the symbolic expressions of death and rebirth through the use of artistic interpretations of the scarab beetle, found carved on Phoenician ivory dating back to 8th century BC (Macdonald, 1988; DeSpelder & Strickland, 1999).

Early depictions of death themes are graphically portrayed through early paintings, one of the most famous being Michelangelo’s Sistine Chapel (1508 – 1512). Throughout the middle ages the art of Western Europe provided a multitude of expressions of death, growing “out of widespread fears about the spread of the bubonic plague” (DeSpelder & Strickland, 1999, p.29). Munch’s ‘The Dance of Life’ represents his attempt to express human fate, as does Fritsch and Ilse, whose 1988 book ‘The Anguish of Loss’ puts poetic interpretation to the photos of sculpted work. This sculpture was the media used by the author to express the deep anguish of losing a child.

The making of a quilt has been both a personal and social mechanism used to express grief and death throughout the nineteenth century, and recently revised

with the emergence of AIDS related deaths (DeSpelder & Strickland, 1999). Survivors of AIDS victims not only commemorate the life of their lost person, but also are provided with “a focus for physical working through grief” (DeSpelder & Strickland, 1999, p.31). This worldwide visual expression encourages our society to grieve openly, “to defy the suppression of grief and create new modes for its expression” (DeSpelder & Strickland, 1999, p.31).

2.7 THE CULTURE OF GRIEF

Death, according to Charmaz, “is a dimension of human existence shaped by values” (1980, p.12). Although such values are individual they are heavily influenced by cultural diversity. Society and culture dictates to people how they should act during all phases of the dying process, including where to die, mourning and burial customs, funerals and memorials (DeSpelder & Strickland, 1999). Death is not only explored so as to give meaning to it, but the way death is dealt with is heavily influenced (Charmaz, 1980; Walter, 1991; Averill & Nunley, 1993; DeSpelder & Strickland, 1999).

Rituals identify transition and mark rites of passage, and death is no exception. They are designed to assist mourners by allocating a role to fulfil, giving loss meaning and realigning support networks and commitments (Averill & Nunley, 1993). Rosenblatt found that almost all cultures have an emphasis placed upon the importance of loss, with most also having a belief in an afterlife (1993). The specific expression and definition of rituals surrounding death however vary greatly across cultures, ranging from welcoming death to denying it (Averill & Nunley, 1993; Rosenblatt, 1993; DeSpelder & Strickland, 1999).

Because of a general move away from formalised religious and cultural groups, western society has lost knowledge in the roles expected by the mourner (Charmaz, 1980; Rando, 1984; DeSpelder & Strickland, 1999). However with assumptions being questioned, meaningful responses are being searched for,

with new rituals and values being formulated to suit our changing society (DeSpelder & Strickland, 1999).

Traditionally, death has been considered a taboo subject in Western Society (Kellehear, 1984; Kington, 1989; Walter, 1991), yet by avoiding it does not go away. Walter's study discusses the ideal "that it is the modern individual, not modern society, that denies death" (1991, p.293), further emphasising that the taboo is disintegrating and as such death, rather than being forbidden, is hidden (1991). By avoiding death we "only limit our choices for coping effectively" (DeSpelder & Strickland, 1999, p.37).

The avoidance or denial of death also leads to society being uncomfortable around the bereaved; "the loss of a coherent language for discussing death (which) leads to conversational unease" (Walter, 1991, p.293). If uncomfortable with the expression of grief, those around the bereaved may give subtle messages not to express their feelings and not to feel the need to grieve (Worden, 1987). A common example of this is that, rather than listening and supporting expression, society tries to distract the bereaved from their grief (Gorer, 1965; Worden, 1987).

Due to changes in culture and western society, death has been taken out of the family's hands. Thus it no longer has a familiar place (Walter, 1991; DeSpelder & Strickland, 1999). The process which has been a natural event for millions of years has now become a medical process, with technological innovations not only postponing death itself and determining and influencing when and how people die, but also taking over the care of the dying (Charmaz, 1980; Walter, 1991; DeSpelder & Strickland, 1999).

2.8 INDIVIDUAL PROCESS

Stating that grief is an individual process may seem self evident, but the encouragement and exploration of individual expression has only recently begun to be explored to its full potential within the new paradigm. Some modern theorists, such as Parkes (1993) and Rando (1984), did discuss the expression of individuality. However with its dominant stage theme, the nature of their theories left limited room for self-expression.

Writers as early as Shand (1920) expressed the idea that grief and bereavement is so complex and individual that it is almost impossible to show insight into all of its characteristics. This theme was emphasised in several works which were to follow (Bowlby, 1961; McKissock, 1989; Carter, 1989; Lev & McCorkle, 1998). To those who are grieving McKissock advises “you are the only one who can feel what you feel; you are the only one who can determine how to express what you feel” (1989, p.27).

Individual expression is much more a core theme of the work of new wave writers. When discussing her findings of thirty narrative accounts of grief, Carter found “people ‘held’ and ‘let go’ in highly individual ways” (1989, p.356), finding it a burden to behave in ways they felt they ‘ought’ to. This has led to a pretence in behaviours of either grief or recovery, and a reluctance to express or talk about their actual feelings (Carter, 1989).

2.9 STORY TELLING

The need for mourners to relate their story, telling of their grief and loss, is an important theme to emerge from the literature. Already discussed in this chapter under the subtitle ‘The New Wave Theories’ (see page 31), are the works of Walter (1996), Vickio (1999) and Moules (1998), who emphasised this idea in their theories. Other writers have also discovered the therapeutic benefits of storytelling, to honour their grief and integrating the biography into the survivors’

ongoing life (McKissock, 1989; Leick & Davidson-Nielsen, 1991; Woof & Carter, 1997; & Lev & McCorkle, 1998).

The importance of storytelling, sometimes repeatedly, follows the idea that to tell one's story is to know one's story, so that the details and construction provide acceptance and healing. With this in mind much of the literature emphasises the importance of the clinician to listen, realizing how necessary this process is for the bereaved to find meaning. "It is critical that clinicians listen to and respond to patient and family members' expression of their needs" (Lev & McCorkle, 1998, p.148). This is especially important as friends, family and society in general tend to deny this need, often due to their own discomforts or inability to provide what they may see as appropriate responses. If society doesn't understand or recognise their needs, it tends to pathologise it (Moules, 1998).

2.10 REACTIONS & DETERMINANTS OF GRIEF

2.10.1 Introduction

The literature provides extensive examples of risk factors which may complicate grief, and therefore may need to be identified in order to assist the bereaved. Also beginning to develop is the exploration of resilience factors, or the teaching of positive coping mechanisms by counsellors to assist the bereaved with their mourning.

2.10.2 Risk Factors

Theorists such as Rando (1984) and Worden (1987) explore risk factors in great detail in their work. Rando identifies factors which she feels influence the bereaved person's ability to deal with their grief. The factors are psychological (uniqueness, individual qualities, mental health, past experiences and roles), social factors (socio-cultural, religious, ethnic, economic and educational

supports), and physiological factors (nutrition, sleep patterns, drug use, and physical health). Rando states, “for interventions to be effective they need to be individually tailored to specific grief reactions” (1984, p.43).

Worden (1987) explores the behaviours he would categorise as normal grief reactions, as he feels “anyone counselling the bereaved needs to be familiar with the broad range of behaviour that falls under the description of normal grief” (p.20). He then describes six parameters, or determinants, which place the bereaved at risk. These are; who the person was, the nature of the attachment, mode of death, historical antecedents, personality variables, and social variables (Worden, 1987).

In Woof and Carter’s recent research they explored and reviewed over eighty studies of bereavement literature, which led to the development of a list of risk factors. These included individual factors, relationship with the deceased, circumstances at death, circumstances after death, and economic status (1997). They conclude their extensive review with the idea that it “becomes clinically attractive to consider these risk factors that may predict poor bereavement outcome given the prospect of preventive care” (1997, p.510).

A more recent and comprehensive study was undertaken by Aranda and Milne (2000). The aim was to develop guidelines for risk assessment to assist palliative care providers when identifying family members who may develop complicated bereavement. An extensive review of the literature identified several areas where the bereaved may be at risk. These were; characteristics of the illness, care, and nature of death, characteristics of the bereaved, interpersonal relationships, and characteristics of the deceased (Aranda & Milne, 2000). As a result of this work, an outcome checklist was devised, as well as a Family Relationships Index to assist the understanding of family dynamics and the risk factors to be considered (Aranda & Milne, 2000, p.84-88). Parkes and Weiss also developed a similar tool to assess and measure high risk factors (1983).

Assessment of people who may be at high risk of complicated bereavement, by using risk factor determinants, is recommended in the literature (Parkes & Weiss, 1983; Rando, 1984; Windholz, Marman & Horowitz, 1985; Lev & McCorkle, 1998). The advantages of identifying persons who may be at risk are listed by Walshe (1997) as for health professionals to identify these factors helps to tailor supports accordingly, and the evidence does show improvement outcomes. Due to limited resources, Walshe recommends what resources we do have should be appropriately aimed at those in high risk, and that those who are most capable of recognising risk and accessing help are actually, in theory, at lower risk, thus it is important for bereavement services to help recognise and act upon people in high need (1997).

Aranda and Milne provide four main guidelines for assessment of family members at risk (2000). They recommend that the family members should “be involved in assessment of risk of complicated bereavement outcomes” (2000, p.15), a team approach should be taken in assessment as part of their duty of care, and it should commence at referral and continuously be re-evaluated during care. They suggest risk assessment requires documentation and team review. Lastly assessment requires information from areas including the illness, care, characteristics of the bereaved and the deceased, and relationships (Aranda & Milne, 2000).

The possible disadvantages of risk assessment are that carers may fall into the trap of judging grief as a predictable process, as did the stage theorists, rather than continuous and individual. From a post-modern viewpoint it is difficult to ascertain or define the boundaries of normal and abnormal grief, therefore affecting what would be thought of as risk behaviour (Silverman & Nickman, 1996).

Defining risk factors is a subjective judgement made by staff, which may be inconsistent due to the skill mix, personal bias and educational levels of the staff involved. The timing of the assessment may influence the outcome, as may the amount of available bereavement support, due to resources. Furthermore, there may be difficulties differentiating grief behaviours from other disorders, such as depression, anxiety, post-traumatic stress disorder, and somatic symptoms (Aranda & Milne, 2000).

Although there are disadvantages and limitations to risk factor assessment, the further bereavement workers explore and develop the concepts and categories the more individually tailored and appropriate this approach will become. Its popularity in the literature indicates it is the most commonly used and documented form of bereavement assessment, yet perhaps not the only one. Recently being explored and developed is the potential use of resilience factors in alliance with risk factor assessment.

2.10.3 Resilience Factors

Resilience factors focus upon the positive coping mechanisms of the bereaved, and have the potential to achieve similar goals to risk assessment; primarily to assist the bereaved with their grieving and identify those who may experience difficulties in this area. By using the resilience model this may be achieved within a more positive framework.

The resilience model originated from Hill's 1949 work with family stress. His work described the need for a critical event to occur, family resources, and the family's interpretations (1949). McCubbin and McCubbin further refined the resilience model, emphasising two phases; adjustment and adaptation (1993). This model primarily was designed to assist families in learning to manage illness demands, meet growth and

development of members and to facilitate constructive function, emphasising the importance of fully understanding the demands and resources available (Malone, 1998). As such it has positive implications for bereavement support. This does not, however, suggest that grief is an illness. It develops positive coping strategies through enhancing adjustment and problem solving skills, rather than analysing at risk behaviour.

The Resilience Model is organised into an adjustment and an adaptation phase. The adjustment phase “captures the concept of crisis intervention” (Malone, 1998, p.51) when the family is in crisis, marked by disorganisation. The usual coping strategies are not sufficient, and the emphasis placed upon the illness or loss profoundly impacts upon function and balance. The outcome depends upon the coping skills previously learnt, and the crisis has the potential to “improve the families coping skills or change family patterns so that the family is more functional” (Malone, 1998, p.53). However the event may also incapacitate the family function.

The adaptation phase incorporates accepting change in family function and needs, including the members’ goals, values and expectations (Malone, 1998). To achieve coherence and wellbeing within the family, trust and stability, the family “must also maintain a level of rapport and interaction with the community at large” (McCubbin & McCubbin, 1993, p.45). The main concept of the adaptation phase includes the families level of resilience, family resources, social support, ability to appraise the situation, family schema appraisal, problem solving and coping (Malone, 1998).

This model has several implications for nursing practice, as the phenomenon of illness or loss are better explored within the focus of the family (Malone, 1998). Nurses therefore must have some open definition of family which fits within their diverse culture, and thus can review and identify the needs of the individual within each family. After needs are met according to Maslow’s hierarchy (1976), attending to needs such as comfort and shelter, then assessment can be made to identify the resources needed, and the educational and emotional needs of the family. To achieve this the roles and

relationships, communication patterns, expressions, behaviour control, problem solving skills and autonomy of each member must be assessed (Dale, Glanville, & Hasan, 1988).

The nurse or bereavement worker can further facilitate positive coping strategies through education of services available, advocating for the family in the community, encouraging individuals to talk about their experiences, expectations and decision making, helping families negotiate needs and further develop problem solving strategies, and empower the family in decision making (Malone, 1998).

This model acknowledges and supports a holistic nursing approach, and as such can be used in conjunction with other nursing theories, or curricula such as risk factor assessment. The challenge is that it's success lies in thorough assessment, which is complex due to family variables. With greater development and further research however, emphasising a need to educate nurses and bereavement support workers, the resilience model has great potential to enhance the assessment and support offered to the bereaved.

2.11 REVIEW OF BEREAVEMENT INTERVENTIONS

2.11.1 Introduction

It has been established that bereavement risk assessment is a major theme emerging in the literature. Therefore to fully review the grief process and bereavement support there is a need to explore the benefits and problems in bereavement intervention, when and who should intervene, and the programs and policies presently being recommended . Bereavement follow up programs being implemented are also reviewed so as to understand the extent of bereavement support in society.

The supports offered through bereavement follow up programs must be flexible and positively geared towards individual expression. This is a common recommendation throughout the literature (Lattanzi-Licht, 1989; Trunnell, Caserta & White, 1992; Faulkner, 1993; Lev & McCorkle, 1998; Renzenbrink, 1999). The bereaved use different approaches depending on social context and unique circumstances to deal with their loss (Lund, 1989). The need for bereavement follow up should be assessed individually as it involves a complicated mixture of feelings, needs and behaviours.

Clinical needs of the bereaved in coping with loss and grief led to the development of grief therapy and counselling (Worden, 1987; Benoleil, 1997). This led to the realisation of the importance of supporting the bereaved in their grief. Bereavement programs, however, were found to be developed after other services have been in place for some time, such as hospice services (Lattanzi-Licht, 1989). Not surprisingly it was found by Faulkner that hospices were more committed than general hospitals in bereavement follow up work (1993).

2.11.2 Benefits of Bereavement Intervention

“The very nature of hospice philosophy underscores the need to provide an integrated system of care that takes account of the psychosocial and spiritual dimensions of dying, death and bereavement as well as the physical aspect” (Spehr, 1997, p.11). To fulfil this philosophy bereavement follow up must be offered and integrated into programs.

There are many benefits to the provision of bereavement care, Watts stating, “available research does indicate that particularly under certain circumstances they (follow up bereavement programs) are effective” (1988, p.5). It has been shown that support through a bereavement program can enhance the survivor’s coping ability, teach and identify interpersonal coping strategies, and allow opportunity for those grieving to tell their story and express their feeling (Lund, Dimond, Caserta, Johnson, Poulton & Connelly, 1985; Trunnell, Caserta & White,

1992; Lev & McCorkle, 1998). Follow up programs can assist the bereaved to continue relationships with the deceased after death, assist and promote openness within families, and offer empowerment with the view to liberate and educate the bereaved to find coping strategies in order to deal with their grief (Faulkner, 1993).

Others have found that support enhanced survivor's coping abilities, producing positive changes in feelings and behaviours (Buchan, Clarke, Devereaux, Rhodes, 1990; Small, Engler & Rushton, 1991). Most substantial is the extensive documentation that demonstrates that follow up bereavement support results in increased health status for significant others. Studies have found that a perceived lack of support after a bereavement raises the risk of health consequences from less than twenty percent to almost eighty six percent (Raphael, 1977; McClelland, 1993). The bereaved with follow up support have shown fewer symptoms of distress physically and psychologically, fewer visits to doctors, and have scored higher in health status scores (Marshall & Nieckarz, 1988; Watts, 1988; McKissock, 1989; McClelland, 1993; Jackson, 1996).

The literature suggests that when bereavement follow up is offered, often by the nursing staff, those having difficulty with their grief have the potential to receive support and help, and further referrals to other services (Carter, 1989; Anderson, Bateman, Ingarlinera & Woolf, 1991; Fenner & Manchershaw, 1993; Marquis, 1996; Lev & McCorkle, 1998). There are also psychosocial benefits for the nurse, as they are able to put their good-byes on paper, talk to friends and family, providing a conclusion and disengagement over a period of time (Burke & Seely, 1994; Marquis, 1996; Jackson, 1996).

2.11.3 Problems in Bereavement Intervention

Although there are many benefits to bereavement follow up, the literature also identifies problems. "The main problem in the bereavement services at present

is the lack of agreement in the health services of what should be offered, by whom and for how long” (Faulkner, 1993, p.73). Lattanzi also refers to bereavement support as “a vague and poorly defined service” (1988, p.81).

Victorian research by Spehr in 1997 reviewed bereavement follow up in palliative care agencies in the state. Forty-four agencies participated. Spehr found most agencies did offer follow up, but were not guided by policy or effectively evaluated. Although a variety of services were offered, however, respondents felt they wanted to expand services, offer support groups, and develop policy, risk assessment, and evaluation (Spehr, 1997).

Another important barrier found was lack of resources, both financial and human coupled with lack of time (Lattanzi-Licht, 1989; Spehr, 1997). Furthermore, studies have also found lack of staff education a problem, with volunteers more likely to receive training (Spehr, 1997). Yet inconsistencies may occur when relying on volunteers to provide bereavement care (Faulkner, 1993).

2.11.4 Intervening: Who And When

It is now felt, due to a belief that grief is oscillatory rather than sequential in nature, that anytime is appropriate to offer bereavement support (Trunnell, Caserta & White, 1992). It is also recognised that such care can and should occur before death, as grief may begin from the time of diagnosis (Trunnell, Caserta & White, 1992; Spehr, 1997; Aranda & Milne, 2000). Spehr is of the belief that if a good standard of holistic palliative care is offered by health care professionals, complicated grief can be avoided (1997).

According to one study, nurses were the first members of the team to contact the bereaved in seventy eight percent of cases (Bromberg & Higginson, 1996). If nurses can positively influence the distress felt by the bereaved, as indicated in several works (Carter, 1989; Fenner & Manchershaw, 1993; Lloyd-Richards &

Rees, 1996; Jackson, 1996; Lev & McCorkle, 1998), it would appear then that nurses are essential in the offering of care, particularly in the pre death phase. “Nurses delivering palliative care are in a position to deliver interventions to family members that may ultimately facilitate coping with loss and grief during the patients’ illness” (Lev & McCorkle, 1998, p.150).

2.11.5 Research, Guidelines and Policy

Trunnell, Caserta and White have stated that “for any bereavement intervention to be truly effective, its foundation must be based on what has been uncovered by careful research as opposed to mere clinical judgement” (1992, p.276). Parkes (1987) feels bereavement follow up care is difficult to evaluate scientifically, however, scientific evaluation may not be the most appropriate method. This positivist approach favours scientific based work, following natural science theories and hypothesis testing (Thompson, 1995; Holloway & Wheeler, 1996). Interpretative paradigms are well suited to exploring bereavement follow up programs as they centre upon “interpretation and creation of meaning by human beings” (Holloway & Wheeler, 1996, p.12). Provide is thick descriptive work from an insider’s point of view, which is primarily due to the nature of bereavement work being so person centred. However either approach may be appropriate depending on the aims of the study, the nature of the problem, and the available resources.

The bereavement support literature follows several methodological approaches. One group of studies have documented the planning, setting up and success of bereavement follow up services (Parkes, 1979a/1979b; Anderson, Bateman, Ingarlinera, & Woolf, 1991; McClelland, 1983; Bourke & Seely, 1994; Bromberg & Higginson, 1996). They range from the documentation of the setting up of one particular bereavement follow up program (McClelland, 1983), to reviewing numerous programs (Bromberg & Higginson, 1996). In Bromberg & Higginson’s research various approaches were used, including selecting data from both

interviews and records, thus combining qualitative and quantitative styles of research and finding statistical as well as descriptive data (1996).

A landmark study was performed by Greer, Mor, Sherwood, Morris and Birnbaum (1983) reviewing twenty six American hospices, mandated by Congress in 1979. This study has been described as the most comprehensive of all evaluations of hospice care in the United States at the time (Longman, Lindstrom & Clark, 1989), and concentrated on secondary morbidity, care satisfaction and reporting of grief responses.

Other studies have reviewed the bereavement literature, evaluating which services are offered, how and by whom (Potocky, 1993; Woof & Carter, 1997). In order to determine what was needed to best provide for bereaved spouses, Potocky performed a content analysis of experimental studies of bereavement follow up programs, analysing the data using a coding system and comparing the effectiveness of the programs (1993). Woof and Carter chose a similar method, however they reviewed a wider range of literature specifically targeting how bereavement effects elements of health, and what implications this has for health workers, in particular the general practitioner (1997).

Provision of standards and policy have also been written to facilitate services and service providers, offer performance guidelines for patterns of care, and assist in recognising standards for funding. This is of further assistance when assessing bereavement follow up services, as it gives a benchmark or standard to which the care and service can be compared (Spehr, 1997; Renzenbrink, 1999), as well as emphasising its importance in Ministerial Reports (Victorian Palliative Care Services, 1997).

In 1974 an invitational group of clinicians, educators and researchers, one hundred and twenty five in number from fifteen countries, founded The International Work Group on Death, Dying, and Bereavement (IWG). This group

published a comprehensive set of assumptions and principles regarding bereavement in 1980 and revised these in 1994. These included the recognition of the need for staff education, continuity of services, multidisciplinary approaches, and the rights of the bereaved (IWG, 1980).

Palliative Care Australia, then known as The Australian Association for Hospice and Palliative Care, published guidelines for palliative care services in May 1997, recommending bereavement follow up program and policy guidelines to implement these. Referral protocol and risk assessment were also discussed in this document (1997). A further document by Palliative Care Australia reports key principles which form the base of present services, taken from surveys of Australian palliative care services, almost two hundred in total (1998). This work recommended the principles form a minimum standard expected for service (1998).

At a state level, Spehr researched Bereavement Follow Up in agencies in Victoria, gaining data from forty-four agencies via telephone and mail surveys (1997). This report recommended use of risk assessment tools in bereavement, a variety of program services covering a variety of clientele, the use of a bereavement coordinator, staff education, and the establishment of policy and protocol (Spehr, 1997). Palliative Care Victoria also offers recommendations for bereavement support, including staff education, appropriate supervision, documentation referral protocols and an assessment process to identify family members at risk of complicated bereavement outcome (1996).

The Minister for Aged Care, in a report by the Palliative Care Implication Steering Committee, recommended “The family unit should be offered bereavement counselling and/or a structured follow up program which assists in fostering a realistic, positive and individualised perspective on the reorganisation of life in the early stages of the grieving and recovery process” (Victorian Palliative Care

Services, 1997, p.11), emphasising the importance of bereavement in palliative care services.

Finally, a comprehensive report by Renzenbrink reviewed both international and local research and policy into bereavement follow up, as well as reviewing the bereavement services offered by the Southern Metropolitan Region of Palliative Care. This report developed a minimum standard and guidelines for best practice, for the above regions Palliative Care consortium. It recommended grief be viewed as a normal process, and the bereaved receive compassionate, empowering, flexible and creative assistance (Renzenbrink, 1999).

2.12 BEREAVEMENT FOLLOW UP PROGRAMS

Specific types of bereavement follow up programs, whether by peers or professionals, hospice groups or government funded volunteer organisations, are explored in the literature. Furthermore the specific elements of these programs are reviewed, with research showing the perceived success of these different elements (McClelland, 1993; Fenner & Manchershaw, 1993; Wilkes, 1993; Spehr, 1997).

Trunnell, Caserta and White talk of being confronted by two dichotomies, when exploring and designing bereavement follow up services, that of peer or professional facilitation, and a group or individual focus (1992). Osterweis, Soloman and Green (1984) identify three types, that of professional, mutual support groups, and hospice care (1984). This was extended to a fourth by Parkes to include voluntary organised support backed by Government funding (1987). Other institutions, for example schools, are also developing guidelines and implementing programs to assist the bereaved (Stephenson, 1994; Benoliel, 1997).

All of these types of bereavement service have advantages and disadvantages, most being formulated in response to a need for assistance by those grieving. Professionals, such as psychiatrists, psychologists, and counsellors, are trained and therefore more qualified to address reactions. Their credibility lies with experience, and usually they offer one to one individual care. However they are often expensive, may carry stigma, and are usually run by people experienced in the field of mental health who may consider grief as an illness (Parkes, 1987). The bereaved may also be of this perception, thus looking to the professional for a cure, as one would seek medical assistance for a physical disorder. In spite of these disadvantages Potocky, who analysed nine experimental studies on bereavement programs, found “professionals are more effective than peer counsellors in providing services to bereaved spouses” (1993, p.298).

The advantage of peer support is that it is less expensive, with members being models of successful coping (Trunnell, Caserta & White, 1992). The bereaved, for their own personal reasons, may choose to be with a group without professional guidance (Parkes, 1987). This type of support avoids the stigma of grief as an illness and usually has loose guidelines for selection. However, with no trained counsellors or standard guidelines there is no means to ensure quality control.

Other supports offered, such as volunteer run hospice projects, are restricted to those associated with a patient who has been nursed whilst being on the hospice program. The training received by the volunteers has no standardisation and thus variety of levels of care is inevitable, as is the help offered (Parkes, 1987). This system does have similar advantages to the group counselling, especially if economic factors or negative experiences with professional are an issue.

There is further variety within the hospice run follow up bereavement programs, most of whom offer a combination of components to provide support. Condolence letters sent one to two weeks post death are often used, receiving

positive feedback from those who received them (McClelland, 1993; Fenner & Manchershaw, 1993; Marquis, 1996; Spehr, 1997). Bereavement cards are well accepted as a means of offering support, with an average of eighty percent in Spehr's study of forty-four hospices using this method. Letters, often including information regarding grief and the supports available, and usually sent six weeks to three months post death, were another positively received component of bereavement care (Lattanzi-Licht, 1989; Wilkes, 1993; Jackson, 1996; Spehr, 1999).

Telephone calls to the bereaved was another medium used by several programs (Anderson, Bateman, Ingarlinera, & Woolf, 1991; McClelland, 1993; Jackson, 1996), offering positive support; and resulting in the bereaved appreciating that they had not been forgotten (Jackson, 1996; Marquis, 1996). This further provides the opportunity to tell their story and reminisce, helping the family and friends feel important. Spehr's extensive study found telephone calls were more commonly provided in metropolitan areas, with one hundred percent of services in the area using this component, compared with only eighty two percent in non-metropolitan regions (1997). Wilkes discussed telephone calls as the most used medium in his study of bereavement services being due mainly to convenience, with one hundred and twelve out of a possible one hundred and thirty hospices reviewed using this method (1993).

Home visits, with one to one personal contact, were a service utilised highly by the bereaved. Lattanzi-Licht found eighty three percent of the two hundred and fifty eight participants received a visit from bereaved personnel (1989). This did vary from organisation to organisation, some receiving one to one support from a nursing follow up visit, others from counsellors or trained volunteers. Other research produced similar results, with Wilkes (1993) reporting such personal contact to be the second most used form of support, and Spehr finding in non-metropolitan areas home visits were provided to all one hundred percent of the bereaved, with eighty six percent equivalent in the metropolitan region (1997).

Memorial services were incorporated into several of the bereavement follow up programs, documented throughout the literature (Buchan, Clarke, Devereaux, & Rhodes, 1990; Wilkes, 1993; Bourke & Seely, 1994; Marquis, 1996; Spehr, 1997). The percentage of services that offered this intervention ranged from ten percent (Wilkes, 1993) through to eighty-two percent (Spehr, 1997) in the metropolitan area. Support groups were also set up and run by several organisations, such as community nursing (Fenner & Manchershaw, 1993) or pastoral care (Marshall & Nieckarz, 1988). These are documented to be successful, yet rely heavily on resources such as time, money, and experienced facilitators to be efficient. Spehr found only thirty six percent of non-metropolitan services offered support groups, in contrast to fifty five percent in the metropolitan regions (1997).

Woof and Carter explored over twenty controlled trials of bereavement follow up, in the area of professionally run support, group therapy and trained volunteer counselling (1997). The recommendations from their findings included certain interventions for general practitioners to observe. These included sending condolence letters, recording the death in their notes, information about services available, follow up visits, risk assessment in planning care, and offering professional counselling or group therapy within the practice (Woof & Carter, 1997).

The literature not only discusses the importance of bereavement follow up care, but furthermore stresses the need to recognise the uniqueness of each person's grief when planning and implementing these programs (Lattanzi-Licht, 1989; Trunnell, Caserta & White, 1992; Benoliel, 1997). Furthermore, it is recommended, "regardless of the modality used, adequate training of the facilitator is imperative" (Trunnell, Caserta & White, 1992, p.279). The importance of bereavement education and training offered to staff is a common theme

emphasised throughout the literature (Faulkner, 1993; Bromberg & Higginson, 1996; Lev & McCorkle, 1998).

A further issue which arose in the bereavement follow up literature was an emphasis on flexibility of service, combining several modalities (Lattanzi-Licht, 1989; Trunnell, Caserta & White, 1992; Renzenbrink, 1999). Emphasis was also placed upon a need to offer the bereaved information, in order to empower them to employ strategies of coping (Caplan, 1964; Kline-Bell, 1992; Faulkner, 1993; Lev & McCorkle, 1998).

A final recommendation made by several of the authors was the importance of having realistic and measurable goals and outcomes, in order to be able to evaluate the effectiveness of the support (Lattanzi, 1988; Faulkner, 1993; Spehr, 1997).

2.13 SUMMARY

A detailed analysis of grief theories, starting from the classic works of Freud (1917) and Lindemann (1944), and moving into the changes and developments offered by the modern theorists, including Kubler-Ross (1969) and Parkes (1972), is examined. The new wave of literature is reviewed, incorporating recent ideas including those of Attig (1996) and Moules (1998). These identify a shift in focus of how grief is viewed.

Several important themes became evident in the literature, as explored in the review. They incorporated the way grief is illustrated, the culture of grief, grief as an individual process, and the importance of story telling in bereavement. Also emphasised in grief literature is the importance of risk assessment of the bereaved, and the newly emerging idea of using resilience factors to assist in grieving. Forms of bereavement intervention and follow up vary, and each have both advantages and disadvantages.

Chapter Three

METHOD AND METHODOLOGY

3.1 METHODOLOGY/THEORETICAL PERSPECTIVE

Ethnography is a methodological approach that aims to understand another way of life from the native point of view (Spradley, 1979, p.3). This thesis used ethnographic methodology with a thematic content approach, the focus being upon descriptions of a subculture. The subculture chosen was grieving individuals who were, at the time of data collection, receiving bereavement services as clients of a community palliative care program. The subculture is examined, analysed and compared in regard to their behaviour (Holloway & Wheeler, 1996). It does not propose to generate theory, such as within a grounded theory approach, but aims to generate knowledge and understanding through descriptive analysis of the subculture.

Ethnography is a form of qualitative research, which reports on people's experience and the meaning it holds for them. "Using this method it is possible to hear and legitimate the web of relationships in which the bereaved are involved, including that with the deceased."(Silverman & Klass, 1996. p.22)

Ethnographic methodology can be distinguished from other forms of qualitative research by its focus on the cultural perspective (Wolcott, 1982). Holloway and Wheeler (1996) define culture as "the total way of life of a group, the learnt behaviour which is socially constructed and transmitted" (p.82). It is based on an intense desire to understand the lives of others, learning meanings of actions and events to seek understanding, not just a study of people but learning from people (Spradley, 1980). This is of particular usefulness to this study because it assists

to fulfil the aims of obtaining in depth knowledge of the grieving process and bereavement needs.

The goals of ethnographic methodology are to identify groups who experience a particular phenomenon and gain an insider's point of view of their world. To make explicit what is implicit within culture (Germain, 1986). Making sense of patterns within a culture, gaining understanding of the norms and rules, and making information available are further aims of this methodology. As Strubert and Carpender (1995) declare "cultural knowledge requires an understanding of the people, what they do, what they say, how they relate to one another, what their customs and beliefs are, and how they derive meaning from their experience" (p.91).

This is supported by the work of Goetz and LeCompte (1994), Spradley and McCurdy (1972), Spradley (1980) and van Maanen (1983). This study particularly focuses upon understanding the bereaved, their beliefs and the meaning of their experience in relation to their lives.

There are many advantages to using this methodological style in research. These include the depth of information obtained, giving fuller understanding of the sub-culture to be studied, relationships within it, and of phenomenon. The partnership between the informants and the investigator provides what is known as reflexivity, which allows the subjective and affective nature of humans to be valued and the ability to achieve insight from the data source (Streubert & Carpender, 1995).

Understanding the culture of the group, its beliefs, feelings and behaviours, as well as the norms and values which influence a person's health experience, is an important way of improving practice. As Holloway and Wheeler (1996) state, "nurse ethnographers see the production of knowledge only as a first step; on the basis of this they seek to improve their nursing practice" (p.81).

Ethnography is especially useful to research in nursing as it provides the opportunity to study nursing issues in practice, supplying a rich data source, with the opportunity to explore the holistic nature of society and ask questions relevant to nursing (Streubert and Carpender, 1995). Spradley (1980) feels such studies promote the idea of truth, giving a rich view of human life. Rather than being taken from what we believe to be true, the data supplies realities from the person's studied perspective, which "will lead to a sense of epistemological humility" (p.15).

Ethnographic studies lead to greater understanding of complex societies, or in the case of this work a sub-section of society. The discoveries bring about important insights; they do not pretend to bring forward 'the truth', but rather a truth (Streubert & Carpender, 1995 p109).

The specific design chosen within the ethnographic methodology was that of thematic content analysis, as described in section 3.2 (page 67). The interest is in the phenomenon rather than the individuals themselves, and can be used to generate new hypothesis, demonstrate effectiveness of specific therapeutic techniques, understand variables in history and development, and explore human experience.

There can be a wealth of descriptions and freedom in the amount of data collected and reported, making other studies at times superficial. According to Polit & Hungler (1995) other studies, especially quantitative, "fail to convey some of the richness of real life subject matters" (p.200).

Using an ethnographic methodological approach within a thematic content analysis design to study this particular phenomenon provides the opportunity to learn the perspective needed for such a study, interviewing key informants to provide an understanding of human nature, grief, and the meanings of the individuals actions and behaviour.

3.2 RESEARCH DESIGN

Data was collected through semi structured interview format. This was deemed most appropriate as it encouraged participants to tell their story and explore their grief. A list of interview questions were written, reviewed, and updated as the interviews were performed. Questions were altered slightly to suit patterns that were emerging through the data. This was particularly the case with questions regarding the participant's experience with bureaucratic organisations, not originally considered, however emerging as an important theme within the first few interviews (Appendix 1).

Interviews were conducted at the participant's home at a time arranged by phone, and audio taped with their permission. Data was gathered primarily from the transcripts of these interviews, and secondly from notes taken during the interviews. The interviews were approximately one hour in duration.

The sample consisted of fifteen people presently on a Melbourne community Bereavement Program who have had a family member or friend die between six to twenty four months prior to commencement of the study, whilst being nursed by a community based palliative care service.

Age ranges are given in five categories in an attempt to obtain a respective spread of age groups. The age ranges were 20 – 35, 36 – 45, 46 – 59, 60 – 75, and 76 – 90. This variable was chosen to compare data so as to determine whether the age of the participant influenced their grieving process or the supports accessed in the community. This had the potential to highlight where needs are in the community and if certain age groups are more at risk of difficult bereavement; which could also influence the way bereavement support programs are set up and practice.

Each participant had to be able to speak and comprehend English, as to employ interpreters was not a financially viable option. The participant also needed to give appropriate written consent for the interview. Gender was not considered as a criterion, and there was no deliberate attempt to achieve equal numbers of men and women as the size of this study would not have enabled for a meaningful comparison.

The participant group consisted of three people in each of the age categories, and included three men and twelve women. All had been receiving support from the follow up program for approximately twelve months.

The eligible participant's details were obtained by review of Bereavement files, with permission from the Bereavement Team. A list of approximately seventy letters was sent to possible interviewees, twelve to fifteen in each age category. Letters explained the research and contained two copies of the consent form (Appendix 2 & 3).

Those not required for interview were sent a letter informing them of this (Appendix 4). Telephone contact was made and interview times arranged. The process took approximately three months.

The data was summarised, analysed and interpreted using a thematic content analysis. Thematic content analysis is a "method used to categorise and codify the interview transcripts" (Burnard, 1991, p.461). It uses a category system to produce detailed and systematic themes and issues. The stages taken loosely follow Burnard's (1991) outline and guide. Notes were taken during and after the interviews, with memos made when common elements arose. The transcripts were read with the aim to "become immersed in the data" (Burnard, 1991, p.462). Transcripts were then reread with comments, or 'open codings' (Berg, 1989), written down for almost all of the data. The categories were reviewed and

grouped together under similar headings, producing a list of themes and subheadings. The transcripts and notes were then reread with the categories and subheadings being listed, and adjusted where necessary. Each theme was clearly marked in the margin of the transcripts to easily identify the content. The information was then collated under the themes, ready for analysis and interpretation.

3.3 ETHICAL CONSIDERATIONS

Possible risks to participants:

Due to the nature of the interviews and the topic explored the potential of psychological risk was reviewed. Protective measures taken included participants only being eligible if the death occurred at least six months earlier. Bereavement counsellors were available to follow up participants who showed any signs of distress or requested such after the interview. This was not needed in practice. It was made clear to potential interviewees that participation was voluntary, and the interviewer was multi skilled in managing such a situation, due to eight years of experience in the field of Palliative Care.

Approval: Ethical approval was gained from The Australian Catholic University on the 7/7/99 (Appendix 5) and from the Melbourne hospital participating in the study on the 6/12/99 (Appendix 6). This was gained before any approach to participants was made. Participants agreed to participate after the explanation letter was read and they had the opportunity to have questions answered (Appendix 2).

Security of Data:

Data will be kept for five years in a locked filing cabinet at the university, as required by ACU. This includes transcripts, notes, and tapes. After a five year period the tapes will be erased, with field notes and transcripts shredded by the researcher. The participants were informed of this by letter (Appendix 2).

Anonymity and Confidentiality:

Pseudonyms were used when coding and working with the data, no names were used in the final report. Data was written up in a way that no individual could be identified. Field notes, tapes, and transcripts were seen only by the researcher, supervisor and typist. Consent for the publication of results in an anonymous form in a palliative care nursing journal was included in the consent form signed (Appendix 3).

Previous Relationship:

The participants were chosen from a clientele not nursed by the interviewer so as to ensure there was no previous relationship that would bias the interview, or pose the risk of coercion to participate.

3.4 LIMITATIONS

Possible bias may have occurred, as the participants were aware the interviewer was a nurse from the organization. This is explored further in the Findings and Discussions section (see page 72).

It was not in the aims of the research to prove or disprove theory or hypothesis, and as such the results do not propose to be a statement about the grief or

supports experienced by a wider community. The author recognises that comparisons of gender, economic status, education, sexuality, religion, culture, ability to communicate in English, and ethnicity are sociologically significant, however the study cannot provide comparisons on such areas due to time and resource constraints restricting the size of the study.

Other biases of the author, such as writing from the post-modern viewpoint and evolving new paradigm, were stated clearly in the introduction.

Chapter Four

FINDINGS AND DISCUSSIONS

Traditionally in qualitative research of an ethnographic design the analysis section is separate from that of the interpretation. However for this study it was found that combining the two under each theme provided far greater clarity and consistency, and therefore added to the understanding and meaning of the study results. This assists the reader to comprehend the work, and is methodologically sound, working within the guidelines of ethnographic studies to produce knowledge by describing a culture or subculture (Holloway & Wheelan, 1996).

The analysis or data sections organize the collected material into manageable themes, describing patterns and results from the transcript data. This is followed by an interpretation of the information, giving possible explanation for the phenomena and providing meaning (Holloway & Wheeler, 1996). The analysis section explores the theme in relation to the literature, and gives insight through speculation and explanation.

Nine main themes were identified. The first four are explored in the greatest depth. They are the 'Expressions of Grief', the 'Comforts' used by the bereaved on a personal level, the 'Supports' offered from an external source, and the 'Problems' and difficulties found to affect the grieving. The remaining five themes are 'Spirituality', 'Role Changes', 'Story Telling', 'Age Related Influences', and the 'Recommendations' made by the participants.

4.1 EXPRESSIONS OF GRIEF

4.1.1 Introduction

As discussed the literature indicates that grief, as an individual process, is expressed in many and various ways. There were, however, common expressions of grief that emerged repeatedly throughout this data. It is important to acknowledge these emerging themes without falling into the trap of dictating certain feelings or stages of grief as has been the case in the past. This study recognises these themes, but does not suggest that this is how one should feel during grief, or that these expressions need necessarily to be experienced.

4.1.2 Individual Process

ANALYSIS: Six out of the fifteen participants interviewed referred specifically to the idea that grief is an individual process and must be dealt with in a personal way. One subject stated that “it’s an individual process, you learn to cope in your own way” while another said “nobody can do it for you or tell you what to do, no matter how much support there is.” The need for people to cope in their own way is summarised well by one participant who decided that “the best thing I ever did was close my door and say ‘you’ve got to grieve your way and I’ve got to grieve mine, and in the meantime let me be.’”

INTERPRETATION: The data supports the literature, as emphasised in the Literature Review section (see page 47), suggesting that grief is an individual process. It is one which culture, gender, age and society’s values may all play a role. However, although theorists may agree it is an individual process, the nature of stage theories of the twentieth century left limited room for individualistic expression. Furthermore, society’s interpretation of well-known

theories, such as those of Kubler-Ross (1969) and Parkes (1972), began to cloud the perception of how to grieve, and developed a feeling of having to 'do it right'. This is described by Carter as a sense of "oughtness (which) tended to be a burden that led to a need to pretend either grief or recovery" (1989, p.357). Society's expectations of how a relationship was, or should be, can also influence the process. This could limit the freedom of emotional expression for anyone, but especially victims of abusive relationships, where feelings may involve relief and anger rather than sadness.

It appears there is a move away from such stereotyping and reaction against expectations which have been attached to the process of grieving, choosing instead to 'close the door and grieve in their own way', as one of the participants did. If less strict expectations were placed upon the bereaved they may not feel so obliged to strive for the approval of others and perform the grieving as perceived values demand. It is possible that this is becoming true for many attitudes and behaviours in a postmodern multicultural society. Conversely some people may find solace and support in these behavioural structures which society offer.

Within the view of the grief process being individual in nature, society may slowly recognise the impact this thinking has had not only on how one views grief, but also the support offered to the bereaved. It has a direct influence upon how bereavement counsellors and programs encourage the expression of and stories from their clients and perhaps on what they define as pathological behaviour or abnormal grief. It also influences the manner in which bereavement support is to be offered.

4.1.3 Crying and Sadness

ANALYSIS: Several emotional reactions to grief emerged from participants; the most dominant of these was the expression of sadness, either by talking about their sadness or expressing their need to cry. In fact, this was described by twelve out of the fifteen participants, with nine actually crying at some stage during their interview with the researcher whilst exploring the issues of grief and loss.

Most people interviewed discussed sadness and crying as an expression of their love for the deceased, and explored particular times where they were most struck by the emotional need to cry. Often this was at significant times of sadness, for example anniversary rituals. One participant shared her story of a “deep-seated cry” which occurred whilst laying a wreath on Remembrance Day in memory of her husband; “all my grief came out at that very moment. I’d cried and cried but this came from down here and it just wrenched out of me...afterwards I felt I was washed with tears, I’ve been a lot better since then.” Others also expressed the healing qualities of release through crying, using expressions such as “I’ve had a lot of tears, I think that’s good.”

Not everybody interviewed however felt tears to always be helpful or healthy, using critical comments aimed at themselves and others, especially when crying during the interviews. Expressions used included apologising for being “a sooky sooky la la” and “I didn’t think I’d get emotional, I thought I was over all that.”

Two participants expressed concern over pressure placed upon them, by friends, to in fact show more outward emotion associated with grief. Although both felt crying was appropriate and had in fact done so, one stated “you haven’t time to sit down and burst into tears all day long and think about yourself.” Another widow, whilst shopping up the street, was told, “you haven’t really grieved yet, have you?” to which she expressed during the interview the concern regarding society’s expectations; “do people really expect you to go out and be in tears all the time?”

INTERPRETATION: If there is an expression which typifies the emotion of grief or which is associated with bereavement, it would be that of crying and sadness. Some theorists, such as Bowlby (1961) and Parkes (1972) would argue that crying is an instinctual behaviour used to recall the lost object. It is often the first response of a newborn baby who usually stops crying when put upon the breast. It is often an instinctual response at a death, perhaps with the aim of recalling the lost person (Bowlby, 1961).

Nurturing also teaches that crying is an appropriate response to loss and bereavement. It is a learned behaviour presented through the multimedia of movies and television, as well as clowns and cartoons. Crying is also considered to be one of the two emotions that distinguishes humans as higher beings; “His ruminations finally tailed off in a prolonged consideration of those two qualities, or faculties, which most markedly separate the world of humans from the animal kingdom: - laughter and tears” (Miller, 1948).

Whatever the reason behind crying and sadness, be it nature, nurture or a combination of both, it was the most common expression of grief noted in the data and reviewed in the literature. This could have been influenced by the semi formal, relaxed interviewing style during which participants were encouraged to tell their own story. This is not to say that one must be sad to cry, but that it was commonly found to occur during this study.

Some research has even been performed to analyse what catecholamines, or mood altering chemicals, are present in tears (Frey, 1980). The research helps to explore the notion held by some that tears serve a physiological purpose to remove the toxins produced by stress, thus achieving a natural balance and having healing abilities. The hypothesis proposed is “that the chemical content of tears caused by emotional stress is different from that of tears secreted as a function of eye irritation” (Worden, 1987, p.27).

When analysed, the participants who did discuss or express sadness and cried, showed no patterns in regards to age. One pattern that did emerge however was that it was more likely to occur at times of significance such as rituals or anniversaries. This supports the literature and theories such as that of Parkes (1972) and of McKissock (1989), which discuss this phenomenon. Their views helped explain the study data by proposing that these significant times may often be difficult ; “as special dates approach there will often be some intense pain, both in anticipation and on the day” (McKissock, 1989, p.13).

The data shows that crying and expressions of sadness can be a positive and cathartic experience, for example the widow who cried whilst placing the wreath for her deceased husband, and reported the cleansing and healing nature of her crying experience. Nevertheless, society’s expectations and stereotypes, for example ‘boys do not cry’ and ‘crying shows weakness’ are still prevalent. Not everyone interviewed considered the public expression of crying as healing or healthy, with three participants apologising, being self-critical and possibly seeing it as a weakness; one expecting not to cry as he “was over all that”.

Conversely the research reveals that society’s expectations can place pressure on the bereaved to express this emotion when it may be contrary to how the individual feels like reacting. Two participants discussed this as a pressure, feeling it was inappropriate. This also impacts upon the phenomenon discussed

above regarding society's perceptions of the kind of relationship which existed, and consequently how grieving should occur.

4.1.4 Relief

ANALYSIS: Relief was another emotional reaction which reoccurred throughout the data. The specific word relief was not always used, but the sentiment and idea was the same. This was expressed by six of the participants, over a third of the sample, and often linked with strong spiritual or religious beliefs of an afterlife. The relief centred on the belief that the loved one had moved onto a better world and was no longer in pain or distress, expressed by the bereaved as taking "comfort in the fact he is no longer suffering." Another participant discussed these feelings, finding "eighty percent of the cases I can recall people saying 'yeah, I miss (the deceased) – but I am deep down glad that it is over'". He further emphasised that this is "extremely hard to explain to somebody...people out there may be shocked by what you might tell them; it's another thing to actually go through it".

INTERPRETATION: Grief reactions are commonly thought to be negative or 'down' emotions however, as found in the data, positive emotions were also apparent. Rosenblatt states "reactions to loss that are most frequently part of grief include...'down' emotions. But they many also include virtually any 'up' emotions, with the obvious ones being relief that a long and difficult illness has ended and joy at someone's entry to heaven" (1996, p.45).

As a reaction within the grieving process, relief is far more subjective than some other expressions, such as crying. The bereaved justifies this reaction in terms of the loved one no longer suffering or had moved on to a better world. In the latter explanation, relief was often tied strongly with religious and spiritual beliefs. It could be argued that the wish to believe in a better afterlife masks the feeling of sorrow felt with grief, and therefore may be used as a defence against the pain of

grief. In other words, the relief may be constructed to alleviate suffering. This argument is not suggesting that the person does not feel the pain, but rather, by the spiritualization of grief, the pain can be masked or need not be expressed. This would seem to make some religious and spiritual beliefs constructions which alleviate suffering and a method of self-protection from loss. There is, however, an argument for the importance of feeling relief under certain circumstances, for example when a person has died after a long period of deteriorating health and suffering.

4.1.5 Anger

ANALYSIS: Anger is an expression of grief seen repetitively throughout the data. The anger expressed is in varying degrees of intensity, and is directed at a variety of targets. These included family, bureaucratic departments, the health and medical system, and friends. Nine out of the fifteen individuals interviewed discussed anger they had felt or still did feel. Interestingly, eight out of these nine were in the three younger age groups, between the ages of twenty and fifty-nine.

The anger discussed by the participants was often multidimensional, the family being the most frequent target with seven of the participants expressing anger in some form toward a family member. Several directed this anger at siblings and other members because of what they described as a lack of support, either during the period of illness or when looking after surviving relatives.

Fighting within families during the stressful time before and after death surfaced several times, one daughter expressing her anger and sadness that “it breaks up a lot of families.” In two cases families split from the parents of the deceased over what one partner described as a “power struggle” while the loved one was still alive, resulting in the loss of contact post death. Both participants who experienced this stated that their in-laws blamed them for causing or contributing

to the deceased's illness, making statements including they "feel that I've killed (her)" and "they blame me and the kids for bringing the tumour on."

Anger was often expressed at bureaucracies or government departments, banks, and at what one participant labelled "the system." This anger is discussed in the section titled 'Bureaucracy' (see page 117). They range from anger at receiving letters or bills in the deceased's name twelve months after having changed details, to the insensitivity and rudeness of banks and council department personnel. Anger at various aspects of the medical and health system arose in one third of the participants' interviews, including anger with the hospital system to frustration at contradicting information being given by different team members. This also will be reviewed in greater detail in this study (see page 108).

Anger was expressed at a friend for what was considered to be an inappropriate comment made in one instance, another talked of "ranting and raving" about different issues to a friend, which she later realized was "indirectly related to the death." Furthermore, one participant discussed the expressions of anger and appearing to be out of character observed in her mother's behaviour ; "it is as if she is going through...the anger stage now...nothing is right....she seems to be angry at everyone." Anger directed at God occurred in two cases. One participant freely recognised that her initial reaction to blame God was "quite irrational."

INTERPRETATION: Anger is a common theme running through the work of several theorists, including Lindemann (1944), Bowlby (1961), Kubler-Ross (1969), Parkes (1972) and Worden (1987). Worden believes the "line of reasoning is that if someone can be blamed, then he [sic] is responsible and, hence, the loss could have been prevented. People blame the physician, the funeral director, family members, an insensitive friend and often God" (1987, p.21).

As found in the interviews anger was often projected at family members. This is a concept recognised in the literature, often as the family members are within close proximity; as Kubler-Ross states “anger is very difficult to cope with from the point of view of family...the reason for this is the fact that the anger is displaced in all directions and projected onto the environment, at times almost at random”(1969,p.50). Displaced anger would help to explain the reaction of the in-laws of two of the participants, who felt they, the partners, were blamed for contributing to the illness or causing the cancer. Both had previously enjoyed what they described as a good relationship prior to the illness with the deceased’s parents. Both described the occurrence as ‘a power struggle’ between parents of the patient and the partner.

Feelings of anger at bureaucratic institutions were numerous and analysed in this study under the subheading ‘Bureaucracy’, (see page 117). An example of this anger which arose repeatedly in the interviews, was that of the receiving of correspondence addressed to the deceased. Described by a participant as “opening up a wound and ripping you apart,” it indicated a reliving of the acute pain caused by the initial loss, and suggesting that while such triggers continue, the deceased cannot be put to rest. This is not to suggest that closure and completion is the aim of grief, but rather that, for those who find such experiences so acutely painful, these issues need to be resolved in order to be able to move on and find a healthy relationship with the deceased.

It is documented that a common target of anger is the doctors and nurses, perhaps because they are close at hand at the time. Some of this anger may be legitimate and some may be displaced, but as it is so subjective it is difficult to differentiate or identify correctly. C.S. Lewis writes of anger directed at the medical profession in his autobiography ‘A Grief Observed’, talking of his wife’s demise as “the hopes encouraged, even forced upon us, by false diagnoses...by strange remission, by one temporary recovery....step by step we were led up the

garden path” (1961, p.27). Anger at contradictory information given by the medical and nursing profession was also evident in the interviews.

Although mentioned by only two participants, the issue of anger directed at God and religion is significant. Both were in the younger age groups and this may influence why anger was expressed. If the trend in Western society is to move away from formalised religion, younger participants may be less likely to hold the belief that anger at God is sinful and wrong.

C.S. Lewis, in his autobiography published in the early 1960's, has a common theme running throughout of the questioning of God and religion, expressing anger at both. “Not that I am (I think) in much danger of ceasing to believe in God, the real danger is of coming to believe such dreadful things about him. The conclusion I dread is not ‘so there is no God after all,’ but ‘so this is what God is really like. Deceive yourself no longer” (1961, p.8).

Another exploration of the questioning of God at a time of grief occurs in Elie Wisel's book 'Night', when he questions his faith after watching the hanging of a young boy in a Nazi concentration camp. “Where is God now? ... Where is he? Here he is – he is hanging here on this gallows.” (1969, p.76).

A reluctance to express anger may also be related to the spiritual and religious beliefs still found in society today, that it is a sin to be angry and one should not speak ill of the dead. Such influences can make it difficult to allow oneself to express, especially outwardly, anger towards the deceased. Such anger may occur for several reasons, words unspoken, goals not achieved, for dying and leaving the bereaved alone or anger surrounding suicidal death. If society is reluctant to allow expressions of such anger, they may be repressed or deferred. This may have a direct influence on how bereavement counselling is provided, and how training of these counsellors and bereavement support staff is focused.

The interviews indicated that anger, as a response to grief, was influenced by the age of the participants, with eight out of nine in the three younger age groups (20-35, 36-45, and 46-59). Several aspects may influence this. It may simply indicate that the younger age groups felt greater anger as a result of feeling cheated of the life they expected to share with the deceased, or anger at goals not achieved. Another possible reason is that they may have felt freer to express their anger. Perhaps anger is expressed differently by different generations. The younger interviewees expressed their anger openly, and therefore may have been encouraged or educated to do so. This may be influenced further by the different levels of exposure to multimedia from an earlier age. The lessons learned in formalized education regarding expressing and controlling anger may have changed throughout the decades. Older generations may have been taught not to express anger, or to express it in different ways from their younger counterparts.

Literature suggests that the age of the deceased is an important factor in grieving outcomes, the deceased being in a younger age bracket is listed as a risk factor for the bereaved in many studies (Worden, 1987; Rando, 1984; Milne, 2000). This relates to society's view that death of the young is more tragic than the more accepted death of an older person. "In our society, death at a young age is considered a misfortune" (DeSpelder & Strickland, 1999, p.354).

The above arguments are speculative and there is no way of determining answers from this study. It does however generate further discussion and possible hypotheses for other studies. This in turn could influence how bereavement support programs are designed, how counsellors deal with anger, and how the bereaved are encouraged to express and control such feelings.

4.1.6 Denial

ANALYSIS: Denial was an emotion expressed by three of the participants, one commenting “it was such a shock that I thought ‘it is not happening,’”. Denial occurred both during diagnosis of a non-curable disease and also around the time of death, with another participant expressing “they (patient’s parents) were in complete denial...for a couple of years.”

INTERPRETATION: Denial is a reaction commonly documented in association with grief. Kubler-Ross (1969) includes it as one of her phases of grief and it is discussed in the works of Engel (1961) and Bowlby (1986). Difficulty arises in defining denial, or behaviours associated with it, as it is extremely subjective and leads into the argument as to what is normal grief and what is abnormal or pathological grief. Many traditional theories vary in their definition of normal and abnormal grief and new wave theorists are reluctant to set such guidelines. This is considered to be one of the major criticisms of modern theories. Within postmodern thinking, however, a possible definition of abnormal grief proposed by the author of this work is grief which inhibits our ability to move on or develop a relationship both with the deceased and with others, or has a negative effect upon the future. This too, is subjective and must be considered case by case within the boundaries of ones culture, society, beliefs and reality.

Is denial a pathological process? Many people interpret denial as negative. However, this neglects the facts that this particular instinctual behaviour plays an important role as a coping mechanism, effectively filtering out detrimental feelings until the person is able to cope with them. As DeSpelder & Strickland suggest, “Life may be intolerable without illusion. Whether denial is adaptive or maladaptive depends on the timing and duration of its use and on the nature of the perceived threat.” (1999, p.157) Although three participants spoke of denial

in the interviews, no adverse or damaging effects were observed or discussed. The very nature of the hands-on care required by the participants when looking after their loved ones at home, may influence their ability to experience denial.

It could be argued that our society denies death and as such encourages the individual to do so. Certainly, removing the care of the dying from the traditional role of the family and placing it mainly in the hands of the hospital system, may help to create a situation that encourages denial. To illustrate this point, take the special documentation required by law, from a doctor, to ensure that a patient is not to be resuscitated. When resuscitation is considered standard or normal and death not the norm, is it any wonder that our society denies death? Perhaps this tendency is changing, as DeSpelder & Strickland ask, "is death coming out of the closet?" (1999, p.37), and as the Mexican philosopher and poet Octavio Paz warns; "a civilisation that denies death ends by denying life." (1961, p.60)

4.1.7 Regret

ANALYSIS: Three participants discussed having regrets, either because they were not more attentive towards the patient, or regrets that goals or dreams which they had hoped to achieve together had not been fulfilled. One participant discussed his regret of things said between himself and the patient's family, and between him and the patient herself, wishing he had not nagged her to give up smoking during chemotherapy treatment.

Another told of her experience when she felt that she was unable to cope with nursing her husband at home any longer, and arranged for his admission into hospital. When the ambulance picked him up his last words to her were "how can you do this to me?", then refused to speak to her or acknowledge her presence in hospital for the three days he was there before he died.

INTERPRETATION: Regret primarily evolved around the participant's role as carer. Several participants received comfort from nursing the patient at home, feeling that they had done everything they could for the deceased and this may have resulted in less regret. Regrets discussed, however, included the inability to achieve certain goals or the regret of frustrated words spoken between carer and loved one, or carer and family. An underlying meaning could be interpreted as that time spent with the deceased in home care, especially during the last phases of the illness, needs to be linked with happy memories. But this does not take into account the exhaustion and frustration experienced at such a demanding time, for example, regret closely linked with guilt for the widow who had her husband admitted into hospital during the last three days, later believing that his non-communication could only be interpreted as anger, disappointment and resentment. It is perhaps natural that she would feel burdened by such regrets.

4.1.8 Depression

ANALYSIS: Several participants mentioned experiencing emotions associated with depression. However none actually discussed being clinically diagnosed with depression. Four of those interviewed experienced a range of emotions from feeling flat or down, such as "I've been a bit down again...I suppose it is because I am depressed", through to thinking life has no meaning; "I thought about it and thought what's the point? What's the point of living?" One participant went to the local doctor for assistance before she associated her feelings with her grief.

INTERPRETATION: Depression is almost expected by our society to go hand in hand with grief and is documented in literature as playing a significant role in the process (Kubler-Ross, 1969; Robinson & Fleming, 1989; Bower, 1995). The fact

that no other participant discussed depression may be an indication that they considered such feelings as a normal part of the grieving process.

Problems arise with the definition of depression when related to grief. To differentiate between clinical depression and depression associated with loss is difficult and ideally should be made by a trained professional. Nevertheless, attempts have been made to do so and this has been discussed in the literature (Robinson & Fleming, 1989, 1992). Depression is often used as a label, rather than as a diagnosis, and consequently tends to be placed upon the bereaved by staff who are not trained to make such a diagnosis.

4.1.9 Loneliness

ANALYSIS: A particular emotion experienced by four of the participants was the feeling of loneliness. One felt it was “the worst thing I’ve experienced...you can manage through the day, but the nights and mornings”. This was reiterated by each of the four who felt that nighttime loneliness was harder to bare. Mealtimes were also considered to be lonely times; “I eat on my own...that’s something that took me a long time, even now it effects me but I’m slowly getting there”. Another particular component of life contributing to the feeling of loneliness was a lack of intimacy and/or sex life.

INTERPRETATION: In grief, one of the main consequences of loss can be loneliness, described by one participant as the worst thing she had experienced. All four who discussed loneliness tell how it occurred at nighttime. When the company of workplace, friends, family or activities have past to the more solitary moments of night, the feeling of loneliness can become more intense. In the past this was often a time spent with one’s partner, thus in situations where this significant other has died a loneliness is unwillingly forced upon the survivor.

Meal times were also particularly hard. Historically and culturally meal times are significant. Meals are traditionally used as a time of gathering and sharing, of celebration and togetherness. Thus, if these moments no longer exist and meals are eaten alone, it is little wonder that the loneliness by association may occur.

Loneliness, through a lack of physical intimacy, was also discussed by one participant as a significant issue. This was a gentleman in his mid seventies, and tends to question assumptions that the younger interviewees would be the ones expected to find lack of intimacy and/or sex life an issue. Literature also shows lack of intimacy leading to loneliness, with CS Lewis feeling “there is one place where her absence comes locally home to me, and it is a place I can’t avoid. I mean my own body. It has such a different importance when it was the body of H’s lover. Now it’s like an empty house” (1961, p. 12). This is significant in relation to bereavement counselling and follow up programs, as staff must be comfortable about discussing such issues. Gallagher recommends, “we think of all the sensory stimuli – thermal, olfactory and tactile – that are associated with an intimate, lifelong relationship” (1992, p.12).

4.1.10 Health

ANALYSIS: It was expected, from knowledge gained when reading the literature, that the grief process would affect participants’ physical health. Therefore this area was explored in each interview. When asked if the grieving effected their health in any way, several participants answered ‘no’. When explored further, however, particularly in relation to diet and sleep patterns, it was discovered that eleven out of the fifteen interviewees had in fact been effected physically by the loss.

The most common effect grief had on the participants was change in sleeping patterns, with six describing inability to sleep. Several needed prescribed sleeping tablets, while others requested the same from their local doctors and were refused. Comments relating to this behaviour included “I haven’t slept properly since my husband was alive” and “I walk the place here at night mad for sleep.”

Four described having no appetite, forcing themselves to eat and neglecting their diet, with one person stating she “lost a lot of weight, but I think that’s just natural...something to do with your metabolism.” Nausea was also a common symptom, one participant stating, “I felt nauseated, it was helpful to know that it does happen...you don’t associate it or expect to feel nauseated.” These reactions occurred more often amongst participants who had lost partners rather than those who had lost a parent.

Two participants described lethargic feelings, to an extent that this effected their lifestyle; “I lost motivation, it took me some time to get back into fulltime work,”. Three participants experienced flu and virus symptoms, with one having three bouts of such viruses in the year. Two participants described other family members as having had what they labelled nervous breakdowns, and one young participant experienced a mild heart attack shortly before his partner’s death.

INTERPRETATION: “The biology of grief may have life-threatening consequences” (DeSpelder & Strickland, 1999, p.244). The effect grief has upon the bereaved’s health is a well explored and documented phenomenon. Theorist and authors, such as Engel (1961), Stroebe & Stroebe (1987), Parkes (1972), Woof & Carter (1997) and McKissock (1989) make reference to it. There is “a wealth of literature that has contributed to our understanding of the mental and physical morbidity following bereavement” (Woof & Carter, 1997, p.447).

Although several participants did not consider that the grieving process had had any effect on their health, they admitted to a change in sleeping and dietary habits. With some this could be considered a form of denial, or perhaps the bereaved do not associate physical symptoms with grieving. One widow found herself at her local doctor before realising that her symptoms were expressions of her grief.

The difficulty with associating health and grieving is that the psychological and emotional components are not easily diagnosed. If a grieving widow has three viruses in the first twelve months after her husband's death, is it because she is run down, would it have occurred anyway, or are the illnesses a physical manifestation of emotional issues not expressed? Few of these speculations can be answered, however, one participant made an interesting observation in regard to her recently widowed mother's continuing poor health stating, "she has always got something wrong with her at the moment. I think it is like a little child seeking attention because she is lonely." This judgement could be an example of society's lack of understanding of the reality that grief can negatively effect the bereaved's health.

4.2 COMFORTS

As with the emotional expressions of grief, the activities which bring comfort to the bereaved can vary widely and tend to be somewhat individualistic. The elements under the title of 'Comforts' refer to the personal aspect, or internal processes which assist the bereaved to deal with their grief, offering optimism and hope from a personal perspective. They include the 'Creative Expressions' used by participants, 'Seizing the Day' with the deceased before death, 'Living On', 'Reinvestment in Community Groups', and the gratification of 'Nursing the Person at Home'.

4.2.1 Creative Expressions

ANALYSIS: Creative expression in its many forms is one comfort which plays a significant role for the bereaved. Nearly all the participants discussed activities appropriate to collate under this title ranging from massage to folk art, and from gardening to letter writing.

One artistic expression, from which several of the participants received comfort from was writing. One of them who plans to write a book about her deceased mother stated, "It will make me feel like I will get to know her all over again. She will always be with me." Four people found writing therapeutic, with two others finding comfort from reading material on death and dying, "the journey of the soul", to search for answers and helping "understand why".

Listening to music was found to be helpful, one participant expressing she "gets through with music, it is the only thing I find solace in." Four members talked of music being a therapeutic medium. Another used it "if the house is too quiet."

One third found comfort working in the garden, stating "having the garden is marvelous, I think that it is wonderful therapy". Another offered "when I am in the garden I don't think, my mind just relaxes."

Six participants found comfort from building or visiting some form of memorial or garden, an altar or plaque; "we have made a lovely memorial or headstone...I find comfort in that...to me it is so beautiful" and "my step brother built a nice memorial garden, which is nice to sit around and have a drink and talk". Another participant described a special place as healing, "where I can remember and sit and say 'remember this time, we had a really good time'...that really helps me a lot."

Participating in art therapy was found to be very helpful, one widow stating, "It is lovely to go there. It is not art that you have to be very skilled at, it is fun art." Another found comfort in completing a memorial tapestry for the church. Three participants found comfort in creating a board or wall of photos, or a "wall of memories" as one labelled it.

Media such as meditation, massage and Reiki were also used as a form of therapy by different participants. One lady in her eighties described how "meditation is of great benefit." Another participant chose to receive Reiki sessions for healing on the first anniversary of death, whilst another trained in the art of Reiki healing, using it to help others. Physical activities of other sorts which were also used as grief therapy, included golf, fishing and running. One person who used running as an emotional release stated, "I do not know what I would have done if I had not been running".

INTERPRETATION: The literature has many examples of the use of creative expressions as a form of education about grief and death, as well as being a beneficial tool in bereavement therapy. This has been explored thoroughly in Chapter Two, titled 'Illustrations of Grief' (see page 43). From the data it is clear that many participants found solace and comfort in various forms of art therapy. Participation in these did not prove to be gender related in any way, with individuals choosing their own form of therapy according to their preference and seemingly not influenced by professional recommendations. One third of the participants placed special emphasis on showing photos of the deceased during the interviews in an effort to further reveal whom the loved one was. Three created a designated wall or board just for these photos. One included typed quotes from condolence letters received. Not only did this help to explore the story, putting a face to the person being discussed in the interview, but also helped the bereaved develop a new on-going relationship with the deceased, exploring who the person was, is, and will be to those left behind. Leick and Davidsen-Neilson state that, "if therapists use imagination, we may find many

symbols and rituals which ease the clients work of grieving.” (1991, p.52) This need was highlighted by the participants’ reactions.

Another form of therapy to be used successfully was writing. One participant chose to aid her grieving process by writing a book about her deceased mother, in order to further explore their relationship. One of the new wave theorists, Walter, albeit in a slightly different format, explores writing as therapy. His work develops a model orientated around the construction of a biography to integrate the deceased into the bereaved’s life. His principle medium was conversation with others; however, the concept is basically the same. Walter encourages theorists to explore his model, used to “supplement, rather than replace, the conventional wisdom” (1996, p.20) and this could have implications upon how bereavement counselling is planned and performed. Another therapy similar to the biographical exploration is the use of literature to explore feelings and expressions of grief, as found by two participants, reading materials on death and dying.

Memorial gardens were found to be therapeutic. For many centuries memorials are ways societies, in many cultures, have chosen to remember and respect the deceased. “Grave markers and monuments are examples of ways in which people have traditionally chosen to honour and remember the dead.” (DeSpelder & Strickland, 1999, p.298)

In a different form of expression, several participants found working in the home garden therapeutic, helping to relax the mind and soothe the pain of grieving. A release through physical exertion, but perhaps also a sense of growth and rebirth.

“Music...calls forth strong and good memories. So music can also become part of grief work.” (Leick & Davidsen-Nielsen, 1991, p.52) Whether or not the use of music was recognised as formal therapy, it was certainly found to be helpful to

four participants. The growing popularity of music therapy in areas of bereavement is becoming more common and is utilised by the organization's Community team (Hogan, 1999). As a therapy it can be used in a variety of ways including memory recall, story construction, symptom control and relaxation techniques (Porchet–Munro, 1993, Hogan, 1998). Music is involved in palliative care and grief work to be “a transformative current that bridges and communicates, re-arranges and transforms, binds and loosens.” (Firth, 1996, p.123)

Meditation, massage and Reiki were also utilised by the participants. These approaches were not age related, as one might have expected. Meditation and massage date back thousands of years and, more and more, are proving to be accepted by the medical profession as complimentary, rather than alternative (DeSpelder & Strickland, 1999).

These therapies, which are highlighted as beneficial, have implications for centres and counsellors who plan and provide supports. Once again the data revealed how individualistic a process grief is. Thus workers in the area must be prepared and educated to encompass many forms of therapy either by facilitating or referring the bereaved to appropriate resources. Perhaps this should be considered in the planning of bereavement support services.

4.2.2 Seizing the Day

ANALYSIS: Over fifty percent of those interviewed were obviously comforted by their positive attitude and outlook on life. For several, this was the attitude taken whilst their loved one was still alive, a third talking about making the most of every day. This was expressed by statements such as, “we lived each day as it comes”, and “let's face it she is going to die very shortly, so the world's our oyster,” with another being thankful that nursing and medical staff encouraged them to achieve goals, in this case a gathering for family and friends, “before he

got too ill.” As a result several participants recommended that palliative care staff encourage those in similar circumstances to make the most of their time together; “recommend to people that ‘yes you’re terminal, but you have time now so use it now, not when you’re too sick.’”

Knowing that they had made the most of their life together, being thankful for the life they’ve had, was of obvious comfort to the bereaved. One widower summed this up by stating, “I was conscious of the treasure I held every day I was with her, so when your mate goes just like that you’ve got no regrets.” Several participants also felt that it was up to them to take a positive or negative outlook in their grieving, making statements such as, “you haven’t time to sit down and burst into tears all day and think about yourself too much”, and another saying, “it’s up to you to make up your mind how you’re going to live your life...you’ve got choice, you can do down the misery road or you can count your blessings.”

INTERPRETATION: Making the most of every day with the deceased certainly influenced half of the participants in a positive way. Several made statements about valuing the time together, both before and after diagnosis. In most cases it appeared to be the way they normally lived, suggesting that the way you live is the way you grieve. Great comfort was taken through the knowledge that the most was made of each moment and they were thankful for the time shared. Several participants discussed their attitude towards grief as an active choice between being positive or negative. In the New Paradigm literature Attig proposes that if we choose to be active in our grief, we can then determine the style, pace and focus of it (1996).

The underlying assumption here and in the data is that if a positive attitude helps make the most of each day. It consequently helps the bereaved to take a positive and active role in their grief process. This, however, is suppositional, as the topic was not explored in enough depth to indicate any conclusions. Wortman and Silvers’ work explored the assumption that “failure to experience distress is

indicative of pathology” (1989, p.350). However their extensive review of studies over a longitudinal time frame indicate that those who do not show intense distress at the time of loss do not tend to show pathological symptoms later (Wortman and Silver, 1989). It may be beneficial to consider these results when planning bereavement support.

There is an assumption that people who are usually positive by nature will perhaps deal better with grief than those who are not. However this attitude would negate the possibility that people do have the capacity to grow and change when facing a life threatening, or major life altering, event.

4.2.3 Living On

ANALYSIS: Encouragement by the deceased prior to death for the bereaved to adopt a positive attitude towards moving on with life was another means which appeared to bring comfort during the grieving process. This attitude, which is grouped under the title ‘Living On’, was discussed by six of the participants and expressed in a variety of ways, the bereaved feeling that the deceased would want them to move on and be positive about life. Statements such as “Mum was very supportive in that way she said ‘don’t grieve for me – get on with life and what’s meant to be’”, “my daughter said ‘Dad would have been so proud of you’” and “my dad wouldn’t want me to do that – he would want me to be happy, not sadly reminiscing his existence” were used to express this idea.

Others feel they must remain positive for the sake of their families, especially for their children. One widow states, “if I let myself go, my daughter would.... collapse.” Another participant credits his deceased partner for his strength and positive attitude, stating, “I love to think that she made me a better person and I

attribute that straight to her because I saw the courage, guts and determination of this person and that's an amazing feat.”

INTERPRETATION: The ability to adopt a positive attitude towards living on seemed to assist the bereaved, especially if this had been encouraged by the deceased prior to their death. It appeared to be beneficial in the healing process, and encouraged the bereaved not to feel guilty about moving on and forming new relationships. This is a very practical way of encouraging a positive and lifelong relationship with the deceased, as is discussed as a central idea in the New Paradigm literature (see page 31).

However if people are encouraged not to mourn for the person who has died, be it by the theorists or the deceased themselves, does this create an expectation of how the person should grieve? As with problems discussed when analysing classic and modern theories (see page 29), this has the potential to lead to feelings of guilt and frustration when the bereaved do in fact wish to express their grief but attempt to repress it.

Living on for the children, and others still alive, was also thought to be an important issue. Such a notion could be construed as negative, in the sense that people are not living for themselves. However if in such cases it provides a means which helps a person through the grief process, the nature of the driving force could be considered positive rather than negative.

4.2.4 Travel

ANALYSIS: Six of the participants found that returning to travel was an important step in the healing process. All of these people had previously enjoyed travel with the deceased, their partners in all six cases, and now have found it a comfort to move on and travel again. Two of these participants planned to travel

overseas with other family members to catch up with other family overseas; one was planning to take a trip with his grandson who intends to “take me to my roots.” One gentleman, who lost a son in an accident only weeks prior to his partner’s death, told of the healing journey that three of his other sons took to the site of the crash.

Families were often encouraging for widows to travel, or complete a trip planned but never taken with the deceased. Another told of her need to “get away from everything here...somewhere I’ve never been, so I wouldn’t have too many sad memories about it”. This was at the time of her fortieth wedding anniversary, not long after her husband’s death.

INTERPRETATION: Travel was found to be beneficial and therapeutic for a variety of reasons. For some it was a pilgrimage, and used as a healing journey in the grief process. The travel was used to complete a journey planned with the deceased, but not taken due to illness, with a possible outcome of finding some closure in the old relationship and moving on to a new bond with the deceased. Travel was also used as a means of distancing the bereaved from the past, using it as an escape from the familiarity of people and place at special times.

The pilgrimage to an accident site for family members was an important and effective healing journey, helping in some form of closure of a chapter, in the seeking of answers and the saying of good-byes which were not possible at the time.

4.2.5 Reinvolvement with Community Groups

ANALYSIS: Involvement in Community Groups provided comfort for four participants. The opinion was put forward that these supports are vital in the helping of the grieving process. Furthermore it was recognised that it would be

easier if the person is affiliated with the group beforehand; “it is hard to start from the beginning”. One participant also felt she would have had the support and encouragement of her deceased husband in regard to her involvement in several voluntary care agencies, stating that she “know(s) he is looking down and saying ‘Okay, that’s the way to do it’”.

INTERPRETATION: Involvement with community groups from a personal level had positive effects on the healing process. With this in mind it is important for bereavement support workers to encourage involvement. One difficulty reported by participants was that carers ceased their involvement whilst looking after their sick relative or friend, thus the encouragement of re-involvement is important. Another option could be to provide volunteer support during the time of illness so as to allow the carer to continue their involvement. Both palliative care nursing agencies and bereavement support staff need to consider the appropriateness of incorporating and facilitating this when planning care.

4.2.6 Nursing the Person At Home

ANALYSIS: A final common theme which was discussed by six of the participants when asked what gave them comfort in their time of bereavement was the achievement and sense of gratification of having nursed their loved one at home. Knowing that they received good care, that they no longer suffered, and that their last wishes (to die at home) were fulfilled brought great comfort and a sense of reward to the bereaved. Expressions used in describing the impact of this include, “she expressed the wish, she didn’t want to leave this place, she loved it. So I felt pretty good about meeting her wishes”, and another stating, “to give a dying person a last wish...she just wanted to spend her last times with her dog...as simple as it is, it’s the best thing you can give someone.”

INTERPRETATION: A great sense of comfort and fulfillment can be found when nursing a loved one at home. The literature states “many people who have cared for a seriously ill or dying relative at home report that the experience was a positive one” (DeSpelder & Strickland, 1999, p.136).

The advantages of home care can include the sense of comfort of actually being at home, which has been described as the “centre of meaningful activity and connectedness to family, friends, and community” (Brown, Davies & Martin, 1990, p.). Home care also adds to a sense of empowerment for both patient and family, allowing self-determination in routine and timetable. It offers a sense of normality and allows for closeness of relationships, emotional and physical, which is not often possible in a hospital setting. Families and carers also may feel the gratification that is possible in the home setting from “reciprocity, a mutuality of care and concern” (DeSpelder & Strickland, 1999, p.136).

However home care can also be a demanding and exhausting time, as explored further in the section titled ‘Carer Exhaustion’ (see page 128). The importance of professional supports was recognised to be of assistance in both data and literature.

The cost of home care to the patient and family can often be hidden but certainly present. Collopy, Dubler and Zuckerman (1990) report that it is home care that bears the burdens in the health care system.

Although there are negative elements to home care, the overwhelming feeling from the data was that to nurse a loved one at home proved to be a positive and cathartic experience, satisfaction being reached both by patient and carers.

4.3 SUPPORTS

The supports received by the bereaved differ from the comforts, as they are provided by external sources. They have been grouped into the sub-categories of family, friends and neighbours, a Melbourne community home care service, a Melbourne Bereavement Program, formal supports (such as groups or counsellors), community groups, schools and work. These are the groups whose support was described and appreciated by many of the interviewed participants. However some criticisms were made when these supports had a negative influence upon the bereaved. Both will be discussed proportionally in accordance to the findings of the data.

4.3.1 Family

ANALYSIS: The one constant discussed in every interview was the support received by family members. This was obviously the main group to whom the participants looked for support. Although five mentioned some negative issues with certain family members, all discussed the positive comfort and nurturing from other members.

Eleven out of the fifteen people interviewed discussed the support received by their children and their children's families. This support had obvious positive effects, whether it was of an emotional, physical or practical nature, or all three combined. Some discussed their children's ability to encourage the living of their life and moving on, whilst others felt the benefits of help with meals and assistance in the maintenance of the household without the deceased.

Many appreciative comments were made about the participants' children and the support received from them, including "I've got a very good family,(my daughter) she is an angel because she does it through pure love and nothing's a

trouble” and “the sorrow is lightened by the presence of my children...they are the main support.”

Other participants told of the importance of sibling support. One person interviewed received obvious nurturing from her sister after her mother’s death, stating, “we’re very close.... she is a bit like a mother to me in some ways only two years older but a lot like my Mum”, and she goes on to discuss how lucky she feels to have this support. Another participant felt her grief was lightened by the support of her husband’s family, whilst others talk of the nourishing bond with the deceased father’s first family, stating it is “nice to have a relationship with them.... (I am) glad that I didn’t break the tie.”

In two cases however sibling rivalry and conflict actually caused further hurt to those grieving. The conflict was discussed, and found to be surrounding anger directed at brothers or sisters for things said whilst caring for the loved one, or for lack of support when caring for the parent left behind. Another participant discussed the hurt felt from her siblings in forgetting the first anniversary of her husband’s death; “this year people have forgotten, which hurt... not even my sister or brother, that hurt a lot.” Despite these examples, most of the support from siblings was found to be positive.

Several interviewees mentioned that parental support played a very important part of the coping with their grief. One states, “if it wasn’t for Dad I don’t think I would have made it through.... he was there for me and still is.” This family support helped survivors with the burden of grief, support which they felt very fortunate to have. One member did discuss some conflict with a parent, but when further explored she expressed that this relationship was “probably a bit strained because she misses him too” (father/husband).

As mentioned earlier although the vast majority of discussion about family support in the interviews was positive, there were still some issues that occurred

which caused upset to the bereaved. One participant found it distressing that her family showed much support whilst her father was alive, however “as soon as he died no-one has been here, they disappeared so I have no time for them either”, choosing to disassociate with these family members. Others admitted that they did appreciate the support but felt there were “points where sometimes they don’t fully understand.”

Two participants had power struggles with their loved one’s parents, thus these relationships disintegrated, both cases ending in a total break in contact with their in-laws from what was once a close relationship. One described the issue as “very hard, as I am a partner and she is a parent. I can not for the life of me get into her shoes, nor do I believe that she can come into mine.” Such conflict, over material possessions as well as over time spent caring for the loved one, not only caused hurt and anger but both participants were left with the impression that they were held responsible for the illness

INTERPRETATION: Family, both from the data and the literature, proved to be the constant and most essential form of support for the bereaved. “Family support can be a key factor in determining whether the bereaved feels supported and encouraged to deal successfully not only with grief per se, but also with the myriad practical issues that follow bereavement” (DeSpelder & Strickland, 1999, p.257). There is a recognition that sharing the grief does not take it away, yet it can assist the bereaved with their grief. As Fritsch and Ilse state; “In sharing the grief and the pain we are still alone with our thoughts, our dreams, our love. Yet, we are together.” (1988, p.9).

In most of the cases discussed, the support from family was positive in nature, parents speaking very highly of their children’s support. This support was of a practical, psychological, and emotional nature. This respect and care most probably reflect the lessons taught by the parent(s) in the first place, the love offered a reflection of that received. Family is the one group which society

teaches that we are able to rely upon, the constant that offers unconditional love. Added to this ideal is the probability that the family is likely to be grieving for the deceased as well, thus more able to understand the pain of grief. These factors may influence the reasons why such positive support and assistance was offered in the interviews.

The family may tend to offer practical supports, such as meals and transport, rather than counselling type support, due to a mutual need to return life to what it was, or moving on with a new life. This has practical implications when planning bereavement support, or when counselling, especially when the family bonds are not what society expects, or are not there at all.

Some conflict within the family structures caused further pain, over issues including sibling rivalry and forgetting the anniversary of death. The power struggle between the deceased's parents and their partners in two cases was a cause of major anguish. Both partners discussed it at length, with ripple like implications in one case as her children not only lost their father, but their grandparents as well. This leads to compounding grief, where the loss is not isolated but multiple. These struggles are not uncommon, with DeSpelder & Strickland discussing "difficulty in grieving was especially noted with in-laws who held the widow responsible for her husband's death and when in-laws acted to dispossess the widow and her children of property" (1999, p.257), both of which occurrences were discussed in the interviews. The blaming of the partner for the death must be considered in the light of displaced anger, which for several cultural, social, and personal reasons is not expressed at the appropriate target. Even if this is recognised by the partner the event can prove to be very painful and scarring.

4.3.2 Friends And Neighbours

ANALYSIS: Another common element which arose in the majority of interviews was the nourishing support received from friends and, to a lesser degree, from neighbours. Nine of the participants discussed how essential the support from friends was, one stating how she has had “lots of help from friends”, and for another it was “not hard for me to find someone to speak to.” On two occasions participants discussed having negative experiences with friends being judgmental and inappropriate. One stated her reluctance to socialise, as she “feels out of place” because the friends have partners, whilst she is adjusting to widow status. On the whole, however, most participants found friends a great source of support and sustenance, one commenting “I’ve got a lot of good friends where I could say ‘I am feeling really bad today’ and you’d go around and have a drink or something.”

Neighbours’ support was discussed by one third of the population interviewed, with four out of five of these experienced being positive. Although one described the neighbours as being the “only fly in the ointment” as far as supports went, others made statements such as a “very good neighbour...came around every week to see if I am alright...everybody offered if they could do anything” with another discussing a neighbour with whom she “had long talks about things that had happened which was good for me.”

INTERPRETATION: The data indicates that support offered by friends appeared to be more in the form of nourishing emotional support, as opposed to family support which appeared to be more practical in nature. Perhaps this is due to the nature of the relationships and what people are accustomed to sharing with friends. A death within the family will effect most, if not all, members. Thus to avoid burdening family with discussions of grief, as they too are bereaved, it may

be easier to talk with friends. Friends from outside the family are less likely to be emotionally attached to the deceased, perhaps making conversation easier.

Both practical and emotional support was discussed and appreciated by participants. Such supports are related to our sense of community and vary greatly, particularly in an era where mobility is far more common than in the past, therefore long lasting bonds are less likely to develop. A negative experience from neighbours and friends must also be reviewed in the light of displaced anger, as opposed to appropriate anger or disappointment.

4.3.3 A Bereavement Support Program

ANALYSIS: All of the participants spoke very highly and positively about the Bereavement Program, except for two who reported not receiving cards and answering telephone messages by leaving another message themselves, which after a few calls was not followed up. Twelve others however reported the bereavement support to be of assistance, stating they “had a lot of help from (hospital name)... I give them one hundred out of one hundred” and “the offers were always there, the letters came frequently for the family... all the information was there and everything was offered.”

Interestingly seven out of the twelve participants who found comfort from the follow up support also discussed that they didn't feel the need to utilise or access the bereavement service, other than receive the cards and the occasional phone call. This theme was typified by expressions including “they've been in touch with me really all the time. I've had the offer to get guidance...(but) didn't avail myself of it”, and “I knew there was a grief line and (the organization name) hospital is still there... it is enough for me.” Two participants did state that although they knew the support was there, they found it difficult to ask for this help and therefore didn't access it, typified in the comment by one that the support is good “but you don't tend to make that move.”

Three participants discussed the Ceremony of Remembrance as being a positive experience, one utilising the opportunity to become involved in choosing music and readings for the service which coincided with the first anniversary of her husband's death. She reported this to be a very healing process, finding the service "very co-operative, right through they have been wonderful." One person attending the memorial service felt it "wasn't quite what I had expected it to be", as she was expecting to talk with others about her experiences. She was therefore referred onto a support group in her area.

There were positive reports about the receiving of cards and letters from the service by many of the participants, commenting in one case that the service was the "only one who remembered the anniversary" of his partner's death, another stating, "it was nice to receive the cards from the hospital and to know that they are there for me when needs be."

On the whole the telephone calls made by the bereavement support team counsellor were appreciated and considered helpful, with feedback including "I think it gives a feeling if you need something you wouldn't hesitate to call" and "the first three months I felt I needed to talk to a (name of organization) counsellor over the phone. One opinion however varied slightly. This participant felt the telephone calls were more upsetting than helpful, stating, "just talking on the phone will bring the memories back more I think, upset them".

Visits made by the counsellors appeared to be of benefit, however only one participant accessed this part of the service, reporting "a lady came a couple of times.... so you know I've had very good support."

INTERPRETATION: "The appropriate expression of bereavement salutations forms part of the mourning rituals that help the bereaved feel cared for and supported" (DeSpelder & Strickland, 1999, p.562). It is recognised that this

support is essential. The Melbourne hospital studied, as a part of their community team, employs a Bereavement Counsellor to follow up family members and carers of those who have died whilst being nursed on the home care program. This is in fact where the participants of the research are drawn from. The program is flexible to suit the needs and requests of the bereaved, however standard letters at six weeks and condolence cards are sent, along with information regarding how to access help if needed. Cards are also sent at the times of the deceased's birthday, Christmas (where appropriate), and the anniversary of death.

Telephone calls are made to offer counselling to the bereaved, with follow up support in the form of referrals to other groups if requested, or counselling visits. The hospital also provides a Ceremony of Remembrance once a month for the significant others of both the community and hospital patients, held in the chapel.

Other services offered are the twelve hour telephone counselling service called 'GriefLine', where an average of three hundred calls are received very month (Renzenbrink, 1999, p.31). A Children's Bereavement Program is offered and coordinated by a psychologist and family therapist, along with education, training, information and library services.

As mentioned one of the aims of this study is to review the follow up service, and other similar services offered to the bereaved. Thus it is no coincidence that all participants discussed it, as the interviewer specifically questioned what supports did they receive from the Melbourne hospital, were they of benefit and how could the services be improved.

From the data analysis it can be seen that the response to the organization's service was a very positive one, with very few criticisms. Other than addressing these criticisms there were no recommendations regarding how to improve the service, even when specifically asked, as was done in each interview. A recent

report commissioned by the Southern Metropolitan Region Palliative Care Consortium to guide and develop a minimum standard and guidelines for best practice in Bereavement Services in Palliative Care, the services of the Melbourne hospital were quoted as being, “equal to the best in the world. The range of services offered enables the bereaved to choose and participate in them according to their needs and interests” (Renzenbrink, 1999, p.33).

Because all participants were aware that the interviewer was an employee of the Melbourne Hospital, they may have been reluctant to criticise it. Furthermore, people with a positive experience of this bereavement support program may have been more willing to give their time to be interviewed, as opposed to those who did not reply and whose experience may not have been as satisfactory. These ideas are speculative in nature, but must however be considered.

“The experience of grief also varies according to the amount of social support available” (DeSpelder & Strickland, 1999, p.256). The literature discusses the importance of bereavement support follow up programs, multiple articles for review have been written (see section 2.11 and 2.12, pages 54 and 60). At a local level several reports have been commissioned to review the follow up services in Victoria, Australia (Spehr, 1997), and minimum standards developed for the fifth Metropolitan Region Palliative Care Consortium (Renzenbrink, 1999).

A policy statement in relation to bereavement support, written by the Department of Human Services in Victoria, 1996, recommends that eighty percent of bereaved persons “resume their usual functional roles and capacities within their family and community...A proportion of relatives of friends (about twenty percent) will demonstrate complex bereavement that requires specialist support and counselling in the long term” (Department of Human Services, 1996, p.25). From the data it was found that seven of the twelve participants, who found comfort from the support, did not utilise the service beyond receiving the calls and

correspondence. Only three attended the Ceremony of Remembrance and just one utilised the home visits made by the counsellor.

The limited utilisation of aspects of the program not automatically received by every person, for example the counselling and grief line, could be partially explained by the comments made in the data such as “I know there was Grief Line and (name of hospital)...it is enough for me.” Although Palliative Care Victoria find one in five of the bereaved need follow up, the strong support from family and friends, along with the automatic cards, letters and telephone calls appeared to offer enough support for the bereaved interviewed in this study.

4.3.4 A Melbourne Community Nursing Service

ANALYSIS: All of the people interviewed discussed the home nursing team, in particular the nurses, in a very positive light. Some of the feedback included “I’ve been nursing three decades and have been around long enough to know.... I’ve not heard anything but praise.... those nurses are absolutely spectacular,” and “for the first time there seemed to be people who cared... who had time to answer questions.”

One of the few criticisms about the service, which actually proved to be more of a recommendation, was that the visits stopped when the loved one dies. This participant felt it would have been beneficial for the nurses to continue follow up visits; “(the nurses became) part of our lives and then it just all stopped... (follow up) would have been really nice.” Only one participant had problems with the home nursing service, the criticism arising from conflicting advice regarding both prognosis and diagnosis from the local doctor, contradicting what the nurses and specialist had said. On the whole, however, the comments regarding the home

nursing service and staff were exceptionally positive; “I guess they’re specialist type of people... (and are) very nice in the way they handle the patients.”

The Melbourne hospital studied (i.e. the ward staff) also received positive reports from participants with comments such as, “the nurses at (name of hospital) are fantastic” and “the nurses were wonderful, extraordinary, all of them.” Only two participants criticised their experience at the Melbourne hospital, and this was due to the aesthetics of the hospital and not the service or staff.

INTERPRETATION: The organization received very positive comments throughout the study. This corresponds with the positive feedback received by the hospital in the form of survey sent to all families or primary carers of clients nursed on the program, and the verbal feedback offered during community visits. Many of the considerations and possible biases mentioned in the previous section must also be taken into consideration here, particularly as all participants were aware the interviewer was a nurse from the home nursing team. The experiences the participants had of the Melbourne hospital were also very positive, except for the two criticisms regarding the aesthetics of the wards. This is presently under review with talk of moving to a new location.

Home care is a service gaining increased importance in the community (Baxandall, Hodder, Redpath & Wannan, 1991). There are several reasons for this. These include increased knowledge within the community of the possibility of being nursed and/or dying at home, increased supports and services, and the “trend toward short stays and quick discharges from hospital...captured in the phrase ‘quicker and sicker’” (DeSpelder & Strickland, 1999, p.135). Thus care giving responsibilities are placed upon community health workers and family members (Johnson, 1994).

4.3.5 Hospital and Medical

ANALYSIS: Not all the feedback regarding hospitals and experience with their personnel was positive. Six participants discussed hospital and local medical staff in a positive light, whilst an equal number criticised and had negative feedback concerning the same. Medical staff, hospital staff and local doctors received a mixture of comments, the local doctors being the subject of the most affirming feedback.

Some of the views the participants had regarding a collection of Melbourne's major hospitals, not including the hospital where this study took place, included "I can not speak highly enough of them (oncology staff)... we wanted for nothing," and "these people are miracle workers and they never forget the people they've crossed paths with." Three people interviewed spoke very highly of the care received whilst in hospital, however two others had a very different and negative experience. A quote from the later group included, "they tortured her with needles and blood transfusions," as in the opinion of the bereaved they kept her mother alive "immorally long", against both the family's and patient's wishes. Another states, when referring to both the general and oncology team of a major public hospital; "I haven't got one good thing to say about them – the nurses and doctors have no time for your questions and no compassion."

The doctors in the community received more positive comments than their counterparts in the hospitals. Such comments included, "I've got a new doctors and she is beautiful... the young ones today are taking it more humanely to their patients. They listen, they're compassionate, and they give you a chance to talk," as well as "my doctor has been wonderful.... same doctor for years and he has been very caring."

The criticisms varied in nature from frustration with differing opinions and changing treatments which contradicted each other, to another example where one lady held anger towards her local doctor for giving her weak, but still self

caring husband a flu injection, which she felt influenced the fact he deteriorated very quickly afterwards, stating “he was burning up” and died five days later.

Nurses in the hospital received equally amounts of negative and positive comments. One felt her husband was poorly cared for stating, “they did not look after him very well. I am not blaming the sisters, it is just the fact that there’s not enough of them to do the work they were called to do,” when he was not showered not shaved for two consecutive days. Another, however, felt the hospital nurses were “extremely supportive.”

Two hospitals provided follow up support which was considered to be of assistance whilst grieving, including the sending of cards and an annual memorial service. One participant reported the memorial service “upset me at the time, but it was wonderful, I got a lot out of it.”

INTERPRETATION: Much of the interpretation of anger directed towards the medical/hospital system has been previously reviewed in the ‘Expression of Grief’ section (see page 78). Thus the interpretation of this will not be re-examined. There were an equal number who either criticised or spoke highly of their experience. Thus care is dependent on the personnel involved. Some hospitals received more criticisms than others, however the study was not large enough to determine any significant patterns, nor was it the aim of the research. One major public hospital received both high praise and scathing criticism of the same ward, thus personalities, the individual nature of grief and illness, and deflective anger must all be taken into consideration.

“The relationship between patient and physician implies a contract whereby each party agrees to perform certain acts designed to achieve the desired results” (DeSpelder & Strickland, 1999, p.194). This relationship is not one of equal standing, with one party holding the power of knowledge. The relationship is also

affected by age and culture, with different generations and belief systems affecting the way both parties view the relationship.

As the patient has a choice of doctor in the community this may affect the higher percentage of positive comments regarding satisfaction with their general practitioner. This suggestion is made upon the assumption that these doctors were carefully selected, perhaps years earlier, due to a good relationship with them.

Unfortunately, in the hospitals doctors are designated, which does not give the option of choice to either party. In addition to this the staff in hospitals, particularly the more junior members, lack experience in the field and may not have chosen, or have interest, in the particular specialty. This differs from the local doctors who chose to specialise in general practice and have at least five years post graduate training. Furthermore the pressures and stressors upon the staff in both situations vary considerably.

One of the criticisms of nursing staff centred on the lack of time to achieve an acceptable standard of care. This is not, by any means, a new concept. Unfortunately, it is an issue the nursing profession is discovering more often in many different forums, ranging from wards to union meetings. It has been recognised in the workforce as such an important issue that changes to staff patient ratios were a major issue of recent reforms made in agreement between the Australian Nursing Federation and the Victorian Government, titled the 2000 Public Sector Decision (Morrison, 2000).

Due to cuts in staff numbers and economic rationalisation, nurses are leaving the profession, therefore incentives to recruit staff were also a major factor of the 2000 Public Sector Decision (Morrison, 2000). Working short staffed, due to lack of available nurses, or working in demanding areas including oncology and palliative care, with difficult patient to staff ratios can lead to increased pressures,

reduced levels of satisfaction, and burnout (Alexander & MacLeod, 1992; Riorden & Saltzer, 1992; McKee, 1995; Valchon, 1995). Valchon's research lists "occupational role (role overload...) and work environment (...inadequate resources...and unrealistic expectations of the organisation)" (1998, p.152 – 3) as two of the three main sources of occupational stress. This is often as nursing under such constraints leads to task orientated, rather than patient orientated care.

For patients the care given under these conditions can exclude some of the essential elements of holistic care. The physical care is often the main priority, and even then was criticised in the study due to time restrictions on nursing staff. However the psychological, spiritual and emotional needs may be the neglected elements of care, even though their inclusion is essential (Jost, 1995; Murray, 1995).

4.3.6 Community Groups

ANALYSIS: Fifty percent of those interviewed discussed the advantage of community groups and the support they offered. The groups ranged widely according to individual preference, including Probis, Red Cross, Legacy, Veteran Affairs, bowling clubs and senior citizen groups at the local council. Comments recommending these groups include, "Legacy were very supportive. I've been very fortunate.... I certainly don't feel I've been neglected" and "I couldn't really say no because they were so insistent, which was lovely." Two participants were involved in volunteer care organisations that they reported as being helpful, particularly with keeping themselves busy and providing company.

Legacy was discussed in a positive light by several of the participants, as was Probis, one person finding the "ladies in Probis group very nice... very supportive... rang up every week for some weeks after (husband) died which

was very nice.” Not all felt this way however, one person venting the frustrations of the protocol to join a group like Probis, stating, “getting into Probis is like trying to join the Mafia! You’ve got to put your name down and then you have to go through a selection thing.... I mean this is for elderly people for goodness sake.” Another expressed anger at a council run community group sending an invitation a year after her mother had died, causing distress.

Other clubs, such as golf and angling clubs, were found to be very supportive, providing “a great circle of friends...they’ve been marvelous to me ever since.” On the whole the interviewees spoke positively in regard to community groups that supported the bereaved.

INTERPRETATION: The nurturing friendships and supports offered by community groups were of obvious benefit to the bereaved, despite the negative comment made at the frustration when joining one particular group.

Noted was the detail that all of the participants who gained support and benefits from membership of community groups were in the older three age ranges, thus being between forty six and ninety years old. This is influenced by several factors, primarily the factor of time availability, as these groups, especially the oldest two (between sixty and ninety), are less likely to have members who are still in the workforce. None of the participants in the two youngest age groups, between twenty and forty-five, discussed membership of any community group, however the majority of these were working, or raising young children.

Secondly, the activities offered by the community groups are targeted at an older generation, and thus more attractive to this population. Lastly, the younger participants often had young and dependant families of their own, whereas the families of the older participants had grown and had families, thus influencing the amount of time required to care for and be with their children.

As the benefits of being a member of a community group were emphasised, it is important for bereavement workers to be aware of these advantages and have appropriate referral mechanisms in place. Carers pre death need also to be aware of the supports of the groups, and encourage and help facilitate involvement, when considered appropriate.

4.3.7 Formal Supports

ANALYSIS: Six participants discussed formal type support, including support groups and counsellors. Three of these declined such help when recommended, one stated, “I suppose if I had needed help I would have been able to get it.” Another requested follow up in the form of professionally run support groups, appropriate information being sent after the interview.

One participant had sought help in the form of a professional counsellor, which was found to be a very positive experience, stating, “I saw the psychologist, I had a couple of sessions with her and she gave me a tape so I can meditate at home.” Lastly, one participant accessed formal supports, including parent line and drug line for assistance with a family member, but felt the information given was “what I was already saying.... so I am looking for answers and no one is giving them to me.”

INTERPRETATION: Formal supports were considered to be both helpful, and in one case unsupportive. The later case was left frustrated, yet recognising she was searching for answers which were not likely to be found at the present.

Counsellors have an obvious importance in grief work and bereavement support, particularly when specifically trained in the area. “Recent decades have also seen increased emphasis on counselling and therapy following bereavement” (DeSpelder & Strickland, 1999, p.547). As discussed in the literature review of

the New Paradigm (see page 31), there is a great need to tell one's story. However society, friends and family may not always be the most appropriate media. Counsellors therefore are another alternative to provide the listening party, as well as recommending and encouraging different therapies and tools to express the story, such as the tape given to assist meditation.

As explored in the literature review, group work has a very important place in bereavement support (see page 60), accessed by one person in the study. "Some groups are composed entirely of peers; others are facilitated by a trained professional or lay counsellor" (DeSpelder & Strickland, 1999, p.258). The type of group chosen is a personal and individual decision. These groups are another forum to share one's story with people in similar situations and to listen to other accounts of grief. Furthermore, by telling their story the person gets to explore the new relationship developing between themselves and the deceased, getting to know them again and moving onto a never-ending relationship.

The lack of access of formal supports is a multifaceted issue. Perhaps, as mentioned by another three participants, the support was there but they did not feel the need to access it, feeling the supports they did access (primarily family and friends, the organization's resources and community groups) were adequate.

However, an underlying assumption in our society that asking for help is a weakness needs to be explored in its relevance to the above. If people do not avail themselves of supports, they may not be receiving all that is needed or available. This may be influenced by many factors, including cultural beliefs, generational differences or the terminology used by bereavement counsellors. The title itself may suggest a power imbalance that consists of one party needing help, or not coping, with the other party being the expert with the knowledge to assist.

Lastly, the idea of what counselling can offer may need to be clarified, a prospect needing to be explored if planning bereavement care. If areas of society associate or assume that seeking help and counselling will provide answers, or inform them about the way to grieve, then it must be clarified that the role is actually to facilitate and support, teaching coping strategies and encouraging expression, rather than solving problems and answering the unanswerable questions.

4.3.8 Schools

ANALYSIS: Only two participants talked about the supports offered to their children by schools. One reported it depended greatly on the school, as she received mixed reactions of support; one school being “great”, the other - the local religious primary school - provided little assistance in her opinion, because they “probably think they’ve got God.”

INTERPRETATION: Few of the participants discussed the supports the schools offered, primarily as only two had children of this age group. As with the hospital system discussed earlier, the data reflects that this support appears to be only as efficient as the personnel who provide it. Reports were both positive and negative, mostly the later.

Some schools in Victoria, Australia, have introduced a program called ‘Seasons’, a grief and loss program run by The Catholic Family Welfare Bureau. It aims to allow children the opportunity to express and normalise their grief experience, further supporting and training teachers and staff to assist children in dealing with loss and grief (Payne, 2000). Neither of the participants, unfortunately, had their children at schools that implemented this program. The literature also provides works which give guidelines and advice to classmates and school teachers when

dealing with a schoolchild who is grieving, including Kelly's 1990 work "Dealing with death: a strategy for tragedy".

One Melbourne private school was described by a participant as finding it hard to understand the support needed, with the child "just saying to the counsellor what the counsellor wanted to hear. She would come back to me (child's mother) and say 'he is okay and that he has accepted it'(father's death). I could see that he was not fine and he hadn't accepted it." Unfortunately for this family the experience proved to be very negative and distressing, as the son was suspended after an argument with a religious brother and teacher after questioning, "why is God not helping my father and why do miracles no longer occur as they did in the Bible?"

The above mentioned pupil's mother felt the school showed very little support and understanding in recognising his call for help, and in her opinion he ended up in trouble "because they had no answers for him." This resulted in him leaving school shortly after this experience. This has had further negative implications as he is unemployed, and his mother suspects drug abuse. The experience has left her very concerned and frustrated, feeling unsupported by the community, and feeling it offers very little advice or possible solutions, even after several attempts to access help.

4.3.9 Work

ANALYSIS: One third of those interviewed discussed their work places as a provision of support, both whilst caring for their loved one and afterwards whilst grieving. All of the experiences were positive, one person stating that, "going back to work was the best thing", another grateful for the ability to work part time during the illness and being given time off when needed.

INTERPRETATION: One very encouraging set of results to evolve from the data was that concerning the support participants' places of work offered. Places of employment from this study were very helpful both whilst nursing their loved one and also whilst grieving. Practical assistance was offered in the way of offering the participant part time work when appropriate and time off when needed. Such flexibility has obvious positive implications, allowing for the needs of the worker to juggle formalized work along with the demanding role of carer and family member to a terminally ill person. Discussed also was the encouragement and emotional support received in the workplace. This may be due to the current work practice of offering more flexibility with part time employment, and also the emphasis placed upon value of the employee.

The literature also provides numerous examples of work to assist both managers and colleagues when supporting a bereaved worker (Stanley, 1998; NARLAG[SA], 1999; FASAP, 2000; Fitzgerald, 2000).

4.4 PROBLEMS

The participants of this study, and evidence from the literature, have emphasised the positive support received whilst grieving, the comforts which assisted, and a range of expressions people used to express their grief. However there were also problems faced by the bereaved when dealing with grief. Those particularly discussed were arranged under the following headings; 'Bureaucracy", the 'Hardest Times', 'Inappropriate Comments' made by members of the community, the problem that 'Support Stops After the Death', 'Carer Exhaustion", the 'Inability to get Help', and death being considered a 'Taboo' topic.

4.4.1 Bureaucracy

ANALYSIS: There were several areas which arose in the data that caused distress and upset to the bereaved, several of which were common to many participants. The first of these to be analysed under the title of Bureaucracy includes participants' experiences in their dealings with authorities, such as banks, local councils and government welfare agencies. Six of the participants had significant complaints about the banking system and poor treatment by the staff of these institutions. One experience was of a participant who, after explaining to the teller her situation and presenting her husband's death certificate in order to close a joint account, received the response that the teller "still insisted that both signatures are needed to close the account. I burst into tears it was all too much. They just have no understanding."

Another participant, when dealing with the bank, felt they were "very rude" and had the attitude of "it is not my problem." A third person, not knowing Power of Attorney ended at death, attempted to access the name of her deceased mother's solicitor to finalise funeral payments left in the will. Although she had documentation regarding proof of death, the bank manager refused such information to be given, even after statutory declarations had been signed. The participant felt "she was so rude... we didn't need all that. It was very very stressful and I am still cross with The..... Bank. They are not people orientated".

A further participant felt torment at having to explain his situation over and over, repeating his painful story to different personnel as they were unsure of who and how to handle deceased accounts and similar requests; "I got really sick and tired that the front window of everybody didn't know which department to send you when it comes to something like that."

Other participants experienced anger towards banks for similar incidents including the receiving of letters in the deceased's name months after such details had been adjusted, one widow stating, "as time goes on I find it more upsetting." Receiving of letters was also a criticism made of other organisations,

including local council correspondence, bills for gas and water accounts and ambulance charges. This was found to be distressing by one in five of those interviewed, with participants finding it brought on fresh bouts of crying, stating “each of these experiences is like a stab with a knife, opening up a wound and ripping you apart.”

Anger was also directed at the banks for reasons including the refusal to continue to provide a bankcard, the “girl down the bank said you can not have it now that your husband’s died”, even though the widow had paid the account all her married life. Added to this anger were the feelings that the banks are “very demeaning towards women.” Others became “furious” with the bureaucracy and paperwork involved in changing accounts and seeking assistance, saying “I am so cross my blood was boiling.”

Two participants were particularly upset by the transfer or cancellation fees attached to banking procedures, one discussing the upset at having money withdrawn for withholding tax, which she states she was never told about. Another explains that he “found how expensive it is to die,” as the cost of closing or transferring accounts, refinancing loans and a mortgage totaled “\$3,500.” Not only was his ability to continue payments questioned, the bank not taking into account that there had “been one income for two years due to cancer”, but he found that when dealing with banks he “started to become the bloke that would go...’cut the bullshit of how much you really care and what’s it going to cost me?” This was the issue he described as “the one thing that really hurt... that really made you a little bit mad.”

Other services, both governmental departments and privatised sectors, came under criticism from the participants. One government welfare agency in particular was criticised by three separate persons, one stating it was distressing for her mother who expressed to her “they’re going to make all of us older people want to die... with all the continuous forms.” A second participant described this

agency as an “absolute disgrace with its petty bureaucracy” after his dealings with the organisation.

Another participant discovered inconsistencies with government agencies, who paid one child benefits, yet labelling her other child ineligible and questioning why there was such a drop in income, even after she produced the death certificate of her husband and proof he was the sole income earner pre-death. Criticisms were also made that it took months to initiate payments yet stopped the day a person was no longer eligible, furthermore finding the personnel rude and inappropriate, stating, “these people need education to understand what it is like for us, and not give us such a hard time because of bureaucracy.”

Three people described dealings with local council as a negative experience, causing distress and upset. One found them to be “very officious and very nasty to me... in their tone and manner,” further recommending they “need a lesson in PR.” This was her finding when she attempted to change the name on deeds, rates and correspondence, which she further discussed as a problem due to the expectation that such be done immediately, whilst “you’re still grieving and trying to come to terms with everything.” Another discussed the issue of on going problems with the local council over the water rate title, which she finds “quite upsetting at times, it has gone on and on.”

Individuals who had had a negative experience in their dealings discussed a variety of other agencies. Two participants criticised the ambulance service, one receiving a bill in a dead child’s name after they had removed her body from the address only weeks earlier, and another described the officers as “very rude and impersonal.” There was a requirement to get a separate statutory declaration from the police for every legal transfer, with one of the bereaved expressing frustration at such time consuming bureaucratic requirements. One interviewee had had all assets frozen for fifteen months post her husband’s death, primarily

due to the executor of the will, leading her to realise “the executor has so much power and you don’t have any... you don’t have any rights at all.”

Several participants told of stories where organisations, ranging from the RACV to a local gymnasium, phoned asking for the deceased many months after the death, often when accounts or membership had been previously settled or cancelled. This was described to be very upsetting. Another tells of a real estate agent who befriended her recently widowed mother, trying to get her to sell the house, reporting “she telephones me crying, he gets her at vulnerable points.”

INTERPRETATION: A major aspect of the data collected evolved around complaints and criticisms of what has been labelled bureaucracy. This was an aspect of the grief process and supports not initially expected by the researcher, thus not in the initial set of questions asked. However, when the issues arose repetitively during the interviews, the importance and recurrence of this indicated the need to pursue the area further, and thus incorporate a question about it. It was generally asked, when discussing supports received, whether there were any issues, positive or negative that the participants’ experienced when dealing with bureaucracy such as banks or government departments.

The criticisms have been discussed in detail in the data analysis section, covering areas such as paperwork, rude and inappropriate treatment by staff, lack of knowledge by staff or procedures, banking fees and taxes surrounding paperwork after a death, the sending of letters in the deceased person’s name and telephone calls asking for the deceased months after their demise.

Ideally, as Blauner states, “The bureaucratic aspect of death in modern societies is designed to prevent disruptions and preserve the equilibrium of social life” (1976, p.35). However in this age of economic rationalisation and ever-changing technological advancement this seems to contradict what the data speaks of as experience. Such bureaucratic ideals may originally have been designed to

make life for the bereaved as easy as possible, however this is not the present day experience according to this group of people.

Several of the participants recommended there be staff education in banks and departments, such as Government Welfare Agencies and local Councils, with the education and training being focused on public relation skills and specific skills to work with bereaved customers. On an even more basic level some participants felt the frustration of encountering staff who were not aware as to which department or service officer to send the bereaved customer to, thus requiring a painful explanation to be told repetitively to strangers. Training and education in this area was recommended and would certainly appear appropriate.

As death and grieving is still an issue our society is not always comfortable discussing, the staff may not have known how to handle the situation, and thus need further training for their own benefit and confidence when dealing with such matters. It is understandable that they may have never experienced a close death or dealt with the bereaved beforehand.

Due to the large amount of participants who discussed the staff they encountered as rude and uncaring, the issue cannot be simply disregarded as the over sensitivity of the client or misplaced anger and frustrations. These may have influenced the significance of the experience, but the frequency of occurrence certainly reinforce that this is a major issue and stressor of the bereaved in our society.

In a time of economic rationalisation and computer technology it could be questioned whether there is too much emphasis placed upon employees to have computer and keyboard abilities rather than interpersonal relationship skills. Once again, this may indicate that each service is only as good as the people it employs and the training they receive.

4.4.2 Hardest Times

ANALYSIS: When asked what people found to be the hardest times in their grieving process, the answers varied greatly. One third felt the anniversaries were the hardest, whether it is the anniversary of the death, a birthday or a wedding anniversary. These dates were particularly difficult if others didn't remember the significance of the day.

Three other participants described Mothers' Day and Christmas as the hardest, one stating "you don't have that place to congregate anymore, so that makes it hard", after the loss of her second parent. Another two described family events involving the growth of the children, such as a son's wedding, as particularly difficult.

One fifth of the participants described watching the deterioration and illness of their loved one as significantly painful, expressing statements such as, "I suppose the hardest time was watching her get weaker and weaker and going", another saying "his demise was hard to watch... he tried to fight but what can you do?" Two interviewees, when asked the above question, responded with similar answers indicating, "everyday is the hardest." One stated she felt "it never gets any easier, each day there's a hard time", going on to describe a feeling that you "have to get up in the morning knowing you've come to the end of the journey."

Other participants described individual and personal times of particular hardship whilst grieving, varying from meals alone without the deceased, picking up the ashes from the crematorium, or driving alone, to weekends without the shared activity of sailing, described as "the hardest part because they were the best times... out on the bay."

INTERPRETATION: “Survivors may experience a recurrence of grief for a significant loss at various times through their lives” (DeSpelder & Strickland, 1999, p.242). The bereaved, when asked what the hardest times of grieving were for them, described several personal times which caused pain. Common times raised by several of the participants was the times of anniversaries and days of significance. This is a concept discussed in the grief literature and research (Longman, Lindstrom & Clark, 1989; McClelland, 1993; Wilkes, 1993; Renzenbrink, 1999). The actual performance of rituals and ceremonies over centuries and throughout many cultures further suggest the significance of anniversaries. Christians worldwide have performed rituals for thousands of years to remember the anniversary of the death of Christ, at their Easter ritual.

On a more personal level these anniversaries, of the death, birthday and wedding for example, proved to be a very difficult time for the participants. This especially occurred when others did not acknowledge or remember the significance of the event. It is recognised as important in most bereavement follow up programs, acknowledged usually by the sending of a card or letter (see Literature Review section, page 60). Other participants spoke of secondary losses, with the parent figures now both deceased. Not only were they missed, but symbolically and physically so was the central meeting place that their house represented, losing “the place to congregate” as a family.

The absence of the deceased in significant life events may cause onset of intense pain for years after the death (DeSpelder & Strickland, 1999). This was found to be the case for one participant who found the recent wedding of her son a significantly hard time without her mother. These events may be anticipated, and even discussed, for many years before their occurrence, thus in some ways the absence of the deceased signifies the regret of a goal not obtained due to the death. Traditionally these celebrations, for example weddings, bring families together, and the absence of a member is made startlingly clear at these times.

Watching the loved one's demise and deterioration was discussed as some of the hardest times. This is consistent with Longman, Lindstrom and Clark's study which found a large percent of respondents "stated that the time of active dying was also a time of great difficulty" (1989, p.33). Furthermore, this indicated that they considered this time pre-death, whilst anticipating the death, to be a part of mourning. Rando describes anticipatory grief as the combination of both the impending loss and recognising other associated losses (1986), thus whilst planning and preparing for both these losses, the carer is commencing part of the grieving work.

Other participants discussed personal times of particular hardship, indicating once again the individual nature of grief and bereavement. Two referred to "everyday" as being significantly hard. In literature C.S. Lewis indicates similar feelings stating, "it is not local at all...her absence is like the sky, spread over everything" (1961, p.12). Such intense grief further supports the notion that not only is it an individual process, but that the death of a partner may "cut across the very meaning of the other's existence" (Raphael, 1983, p.177).

4.4.3 Inappropriate Comments

ANALYSIS: Over fifty percent of participants discussed being upset and distressed by inappropriate comments made by others whilst grieving. These came from a variety of sources, ranging from school counsellors, friends, families and businesses. Difficulties arising in not "knowing what to say sometimes" were acknowledged by two participants, one stating "I think most people find it difficult. I've had strange remarks at various times."

Comments were touched briefly upon in the earlier section of data analysis titled 'Families' (see section 4.3.1, page 98), where blame was being placed upon the bereaved in two different cases both by the parent of the deceased. The blame

in both cases was surrounding the person supposedly “bringing the tumour on.” Family members also made comments felt to be inappropriate over possessions once owned by the deceased, primarily including possessions. Ownership of a different nature also caused pain to family members, particularly in the case of a granddaughter who, after reading the eulogy at her father’s funeral, had her grandmother comment “thank you for saying those nice words about my son”.

Friends were found “to be a bit critical” and inappropriate in three cases. One participant described her reason for not going out socially was because people did not know how to respond or what to say to her, therefore she feels she is “better off staying at home.” Other participants felt that members of society expected them to “pick up the pieces,” leading to one questioning “every night when I close my eyes – you never forget... so why?” Another participant expressed the concern that people “make you feel like you’re wrong and you can not communicate with them.” One widow recalled a comment made to her by a friend she met whilst shopping down the street stating, “she looked at me and said ‘you really haven’t grieved for your husband have you?’.... Do people really expect you to go out and be in tears all the time?”

One person returned videos late to their regular local shop and explained it was due to the death of her father, only to be “fobbed off and told me it was another ‘story’ so to speak... that upset me.” After many visits to a local chemist, one pharmacist refused to give a repeat on a drug as the participant had forgotten the health care card, the number of which was on their computer, the result being “I got very upset and I broke down and cried because this dying person has been coming here and getting medications here regularly... I just thought where’s the compassion in people?”

INTERPRETATION: “An odd by-product of my loss is that I am aware of being an embarrassment to everyone I meet...I see people, as they approach me, trying to make up their minds whether they will ‘say something about it’ or not. I

hate it if they do, and if they do not” (Lewis, 1961, p.11). Thus both the bereaved and those in contact with them face a dilemma, weighing up the idea that to say the wrong thing may cause pain, as will avoiding the topic.

As inappropriate comments were discussed by fifty percent of participants in the data, the issue is still of concern, even if death is somewhat more openly discussed in modern times. Two participants acknowledged that people do not know what to say to the bereaved, and the literature would suggest that until we lose our discomfort and begin to identify attitudes and behaviours necessary to accept it, we will “keep from lifting the mask and confronting death in a way that is meaningful for our own lives” (DeSpelder & Strickland, 1999, p.38).

As technology now determines how and sometimes when a person dies, it is difficult for society and culture to keep abreast with what behaviours are appropriate. There is also little guidance provided on these matters. The loss of this guidance adds to the problem of inappropriateness when dealing with the bereaved. As the “effect has been so dramatic and rapid that our social response have not always kept pace with such innovations” (DeSpelder & Strickland, 1999, p.37), leading to a use of inappropriate and hurtful clichés or avoidance of the issue in some cases. As Lewis asks, “they tell me H is happy now, they tell me she is at peace. What makes them so sure of this?” (1961, p.24). Such clichés justify death from our own perspective yet discount the pain of the bereaved, limit their expression of grief, and assume we know both death and grief from the bereaved’s point of view.

The study produced ample comments made which angered the bereaved, also discussed in sections including ‘Family’ and ‘Bureaucracy’ (see sections 4.3.1 page 98, and 4.4.1 page 117). Ownership issues and power struggles with families led to inappropriate comments being made at a time where support of members is essential. This is also, of course, a time where people are found to be sensitive and vulnerable. Offensive comments made in one situation may be

less hurtful, or even appropriate in another, the bereaved interpreting or hearing statements differently to how they were intended. This is another form of displaced anger, and if this is what a person has experienced or expects, it may lead to the person being tentative and unsure of what to say and how to support the bereaved.

Criticism of behaviour or response by friends was found to be the experience of some of the participants. Once again the issue relates to how people expect the relationship to be between the bereaved and the deceased, and how certain elements of society enforce their opinion of how to grieve upon others. Such lack of understanding and judgement shows ignorance, perhaps tied in with their own feeling and experiences that they reflect or try to enforce. By educating and encouraging society to look upon bereavement as an individual process which is both personal and unique, and bring death out of the closet and into open discussion and acceptance in many areas of our society, hopefully the bereaved will need to tolerate less insensitive and hurtful comments. Perhaps those supporting the grieving person will be more comfortable in this role. Familiar ease however must not be so casual and open that we overlook the issue itself, as DeSpelder & Strickland warn, “we may find we have confronted only our image of death, not death itself” (1999, p.553).

4.4.4 Support Stops After Death

ANALYSIS: Six of the participants talked about support stopping after death. Two discussed this occurring directly after the death, stating “the house was full of people and the hospital was full of people when (he) was dying. As soon as he died no-one has been here, they disappeared,” in regard to the person’s family. Another talks of support from a community group saying, “they came out to see him.... but the day after the funeral, not one of them has knocked on my door.”

Five participants who had an issue with support stopping talked about this occurring mainly at the time of three months after the death, stating “they’re there for you for the first three months, then it is forgotten about”, another discussing that “after three months, they all think you’ve getting on with your life again.... there’s a bit of a gap where you’re still trying to find your feet.” This certainly caused an issue, one such participant feeling this occurred “because it doesn’t touch them like it touches you.”

INTERPETATION: Even though positive feedback was given for support agencies in earlier analyses, as well as for family and friends’ support, a third of the study group indicated this time being approximately two to three months after death. This is a phenomenon examined in the literature (Longman, Lindstrom & Clark, 1989; Faulkner, 1993; Renzenbrink, 1999), Renzenbrink stating, “research studies have shown that bereaved people are most receptive to help at this time, when the full extent of the loss is only just being felt and family and social support may be drifting away” (1999, p.27).

Bereavement follow up support services recognise the importance of timing when designing their programs and many offer a letter, visit or telephone call around times recognised often as a period of difficulty (see section 2.12, page 60). The participants who found this time having “a bit of a gap” in supports mostly indicated this was from friends and family who may consider life to have moved on, yet for the bereaved this may not be the case. “Paradoxically, at a time when grief is usually most upsetting, survivors often receive relatively little support from family, friends or the community” (DeSpelder & Strickland, 1999, p.240). None of the participants who found this time difficult discussed seeking or applying for extra help, including the contact of grief line, counselling at the Melbourne hospital, joining groups, or discussing the issues with family or friends.

4.4.5 Carer Exhaustion

ANALYSIS: Four participants discussed the stressors of caring for their loved one, not necessarily as a negative experience but as an exhausting one. One felt he “could have done better,” describing the care as being amongst the hardest times he experienced, whilst the other three all talk of how tiring such an experience was, stating, “being awake every two hours, it took me a long time to break that habit”, and “it is very tiring but what do you do?”

INTEPRETATION: A common element discussed by the four participants who discussed the exhaustion faced when caring for the terminally ill was the tiring nature of such work. Sherwood, Kastenbaum, Morris & Wright warn of “difficulties in the physical, cognitive, emotional, or social spheres of functioning that may be experienced by those closely involved with the terminally ill person” (1988, p.150). It is an area of close scrutiny when providing professional care of the terminally ill and their carers, with the organisation’s home care service recognising the need for carers to not only be educated but supported in their care, thus providing services including a spiritual counsellor, social worker, respite care and music therapists working with the medical and nursing staff to support the carer. Also offered is a weekly carer education group offered to all significant others who are caring for the terminally ill. This service provides a two hour education session, along with the opportunity to discuss issues and ideas not only with trained staff, but also with fellow carers.

4.4.6 Inability To Seek Help

ANALYSIS: One issue, which commonly surfaced in four of the interviews, was that although help and support is offered in various forms, participants felt “you don’t tend to make that move.” Another felt that “people say no they don’t need help, but they’re not okay,” recommending it would be better to just go to them,

with the recognition by two participants that “it is very hard to know when to help people or when you are intruding on them.”

INTERPRETATION: Four of the interviewees described that although they knew support was available, they found it difficult to ask for assistance. This is influenced by the underlying current in our society that to ask for help may be perceived as showing weakness, or not coping. This idea is developed further under the topic of supports subtitled, ‘Formal Supports’ (see section 4.3.7, page 113). This issue is complicated due to the vulnerability and pain of grieving, the bereaved not being in the best frame of mind to access supports, or to know what type is best and how to ask for them.

When considering the provisions of bereavement follow up programs it may be of benefit to consider strategies to overcome these problems. One participant recommended it would be best to just go to them. This, however, is most likely to be intrusive, and could be more harmful than beneficial.

4.4.7 Taboo

ANALYSIS: Only two participants actually discussed death as being a taboo topic in our society. The comments made were “I don’t know what it is about death, whether people are afraid of it or afraid to approach it.... afraid to talk about it”, the other stating that “no one talks about it.”

INTERPRETATION: Although fifty percent of participants expressed that people have trouble in knowing how to respond to the bereaved, already explored in the section “Inappropriate Comments” (see 4.4.3, page 124) only two comments were made in the data about death being a taboo topic. This belief can lead to the feelings of not being able to express their grief, or not being listened to.

The literature argues several opinions regarding the debate surrounding death as a taboo subject. Walter explores the option that “there was a taboo, but it is now disintegrating” (1991, p.293). This disintegration may be seen by those working in the field and writing about grief, however not all people feel the taboo has been lifted. Education, experience and culture influence these individual beliefs. Blauner argues as early as 1966 that death is not taboo or forbidden but is merely hidden and no big deal. Another argument is that elements of society can both deny and accept death, thus both sides of the argument can be backed up with ‘evidence’ and presented convincingly (Kellehear, 1984). This would further indicate the individual nature of grief, and the expectations placed upon it by different elements or fractions of society.

4.5 SPIRITUALITY

4.5.1 Spiritual Influence

ANALYSIS: Spirituality was described as playing an important role in the grieving process with many of the participants. All participants discussed spirituality, as all were directly asked how it was influenced by the death of their loved one. The responses varied from outright anger towards God, frustration at religious or spiritual support and a questioning of faith, through to feelings of great comfort from their beliefs.

Over fifty percent of participants received comfort from their religious beliefs or spirituality. Comments made to express this included, “my faith keeps me warm...I am not frightened...trust in the higher being”, and “the spiritual part has helped me completely” in coming to terms with the loss. Two people expressed

the help and comfort gained from a belief in an afterlife, saying “I could not believe that we just bury them and that is the finish of that...otherwise how do we part with them?” and “I guess that is how I get through a lot of things...your spirit’s got to go somewhere...I think I will meet him again.”

One fifth of those interviewed expressed the importance of prayer as a support in their grieving, two of whom reported praying everyday, the third finding great comfort in a prayer book hand-written by her deceased mother. A different three participants discussed the benefits they received from being a member of their church group, who found support and comfort in this, one reporting “they were wonderful, just like family”, another stating, “I found great support because there are people there of similar circumstances.” Two participants talk in a positive light of the support offered by the parish priest, from providing spiritual counselling and the Eucharist, to arranging catering at the funeral.

When exploring the participants spiritual beliefs in the data, it was found that six of these people also at some point during the interview expressed how important such beliefs were before death and during the illness, both to the deceased and the bereaved. Several expressed the important of prayer during hard times in life, including the illness, where one couple “thanked God for all the wonderful blessing received.” Several others report praying with the deceased many days during their illness. One daughter reported her father “did not believe in God until the end, and then he started praying to God”, whereas others found comfort in a “nice belief of going to a peaceful place, love and harmony sort of got me through.”

Two interviewees questioned the support offered by the church, one feeling such help was not offered and therefore she is less tolerant of people after this experience. The other tells of her disappointment when an Anglican nun from her deceased husband’s church and a Catholic nun from her own parish accidentally visited at the same time, neither of whom have been back to visit

again, to her regret. She felt “it would have been beneficial” if such support had been ongoing.

One third of the participants described that they questioned their faith and spiritual beliefs whilst grieving. For one this occurred at the time of diagnosis, whilst for the others they discussed this occurring post death, one describing that “sometimes you ask the reason why, and I have an argument with him (God) every now and again but he usually wins”, whilst another stated, “I started to lose my faith so I am trying to get that back.”

One participant expressed a lot of anger towards God, turning from religion and finding no comfort in it during her time of grieving, as she feels her husband suffered during his illness and death, leading her to ‘tell’ God, “if you have decided to take him - please do.” She further expresses her anguish, asking “I thought why? Why make him suffer?” She has not gone back to the church.

Although such strong emotions are expressed in the data, the overriding feeling from the majority of those interviewed is that spirituality plays a positive and important role in grieving, one person expressing that “faith helped one hundred percent...makes you strong...and humbled, not frightened.”

INTERPRETATION: Spirituality played an important role in the grieving process for many of the participants, in accordance with the statement that “despite the option of unbelief, most people still affirm their belief in God” (DeSpelder & Strickland, 1999, p.521). This finding was based upon a 1990 National Survey in America which reported “seventy eight percent of those interviewed believe in an afterlife, the highest percentages being reported amongst the young adults surveyed” (Kenow & Bolin, 1989-90, p. 73).

Two participants particularly referred to an afterlife, one expressing her inability to part with the deceased if she did not believe in life after death. However it may be asked do people use this belief to buffer the pain of grief? Perhaps this way they find it easier to believe in an afterlife rather than facing finality of the loss without one. The concept also gives meaning to the deceased's life, as ideas of eternity and heaven 'prove' the success of the life lived. Such questions are purely speculative, however the concept of an afterlife is an ancient idea; "the notion that life continues on in some form after death is one of the oldest concepts held by human beings" (DeSpelder & Strickland, 1999, p.502).

The concept of prayer also offered participants comfort and solace. Many of these participants talk of strong religious or spiritual beliefs before the death, with prayer being utilised by some both pre and post death.

Spirituality and religious traditions play an important role in providing guidelines for behaviours associated with major events in life, and death and mourning are no exception. All religions have rituals that guide the bereaved, covering areas from disposal of the body through to the time to mourn. "When people encounter death in their lives, religion can offer solace, suggest some meaning in dying, and provide mourning rituals that ease the pangs of grief" (DeSpelder & Strickland, 1999, p.97).

This study found both negative and positive support was offered by religious groups. This appears to be one further example whereby the support depends upon the specific personnel at the time. Not everyone interviewed found comfort in the church during their grieving, some discussing the questioning of their faith at the time, asking "why", with another describing having arguments with God. This is a common theme not only found in the data but also throughout literature, DeSpelder & Strickland stating bereavement may "evoke a re-evaluation of religious or spiritual beliefs as the bereaved tries to comprehend the meaning of the loss: (1999, p.225).

Lewis eloquently describes the important part religion had in his life, yet its lack of comfort when grieving, when he states, “talk to me about the truth of religion and I will gladly listen. Talk to me about the duty of religion and I will listen submissively. But do not come talking to me about the consolations of religion or I shall suspect that you do not understand” (1961, p.23).

One participant not only questioned her faith, but also expressed great anger at God for what she expressed as the “suffering” of her husband. This caused great anguish for her, possibly worsened due to the traditional beliefs that it is a sin to be angry with God, or question his ways. Anger was found not only in the data but in the literature as well, this being a common theme in Lewis’ autobiographical account of his grief, questioning why he should find comfort in knowing “she is in God’s hands. But if so she was in God’s hands all the time, and I have seen what they did to her here. Do they suddenly become gentler to us the moment we are out of the body? And if so, why?” (1961, p.24-5).

4.5.2 Rituals

ANALYSIS: The important influences ritualistic practice has on the grieving process is reviewed in Chapter two of this study (see page 46). Several rituals were discussed by eleven of the participants interviewed and were individualistic in nature,. Several had obvious religious influences, whilst other were of a more personal level.

The most common ritual found to have given relief to the bereaved was also analysed in the ‘Comforts’ section (see page 88), under the subtitle of ‘Creative Expression’, as the rituals consist of going to specifically arranged areas, such as a cemetery or garden, often where a memorial plaque is laid in memory of the deceased. The bereaved found comfort in just being there, “lighting a candle,” or

“covering the grave with...a carpet of roses.” Six participants discussed the importance of this ritual, three talking of the importance of going to the cemetery. Another found significance in attending Mass on the anniversary of death even though she is not a regular church goer. One found comfort in burying her father’s ashes under a rosebush especially selected by her mother, with a ceremony they composed.

What to do with the deceased’s belongings is individualistic in nature, several “tidied up his clothes and that sort of thing very quickly,” whilst another has “been careful to see that things remained the same as they were when my wife was alive.” One bereaved daughter kept the belongings her mother had made, finding comfort that she “kept all her cushions, things she made.”

Two participants tell of a ritual or custom practiced by the Greek Orthodox church, with a memorial service on the ninth and fortieth day, up until which time no item of the deceased is to be touched. Further anniversary services are held at three, six, nine, twelve months, two and three years. One participant felt he received comfort from this, although it hurt him that his mother-in-law did take the deceased’s possessions before the allotted forty days. Another found this ritual “really hard, I felt it was like reliving the funeral all over again.” After the twelve-month mass, she reported crying for two hours, “asking why do we have to do this? No-one has answers for it...maybe that my husband’s soul can rest in peace”. However even with insight into why the ritual is required the actual performance of it caused obvious torment to her; “it is like reality and I can not accept it that he was here and now he is not.”

INTERPRETATION: Ritual is often found to be ingrained in religions and spiritual belief, with “most societies having developed rather elaborate roles for the bereaved to enact” (Averill & Nunley, 1993, p.82). These were found by participants of the Greek Orthodox Church to guide their behaviour, one finding great comfort and support from such, the other finding the experience painful.

Rituals may provide us with significant roles to perform, however underlying this notion is the idea that grief is still an individual process. This is further emphasised with the description from the current study of how the participant dealt with the clearing of the person's possessions. One chose to keep everything exactly as it was when his wife was living, whilst others cleared them quickly. Important significance here indicates that bereavement courses, carers, friends and family must be careful not to express what is 'right' in certain situations, recognising individual expression as the only correct action. Furthermore, as Leick & Davidsen-Nielsen recommend, "if therapists use imagination (they) can find many symbols and rituals which ease the client's work of grieving" (1991, p.52).

4.6 ROLE CHANGES

ANALYSIS: All participants were questioned as to the influence the death of their loved one had had on the roles in their life, and if these had changed. From the data the most significant role change discussed was in regards to their social lives. Fifty percent of participants described this, with one in three feeling it has significant influence. Three of these people were in the younger two age brackets and were most severely effected with the loss of partners, indicating little motivation to socialise and "feeling out of place" when they did. One reported, "getting the social life going again" in recent times. Another two participants spoke of the adjustments needing to be made socially with the loss of a parent, particularly if a lot of time was spent together.

Several participants found they had lost a common link or bond person, one stating, "it has hit home because we do not have that central person, especially on days like Mother's Day or Christmas." Another discussed his need to take over his wife's role as coordinator of the family, describing his deceased wife as

“the matrix of the whole damn show and conducted the orchestra...anticipated problem, met them and fixed them.”

Children found a need to pick up more responsibility when a parent died, one stating, “the role in the family has changed a bit...more passed to me because I am the oldest.” In some cases this role change was in regard to caring for other siblings, whereas for others the expectation was increased care for a parent left behind, a difficult new role according to one daughter who discussed how she “tries but you just can not fill the gap” of her father, as she sees it now as “my role is protector of mum.”

Two participants had to find employment after the loss of their partners, one after a long time out of the workforce, her previous role being “to run the house and kids.” In this case, it was coupled with the role change of becoming a single parent; “I had to take over literally everything.”

One third of interviewees discussed the burden of having to take over the accounts and finances and run the household. This particularly affected several elderly widows one stating, “I think being a widow is a complete new learning experience in your life. You have got to rethink it all over again and learn to live with it. It changes your entire life.” One stated the new responsibility of organising the accounts; she “sometimes finds that a bit daunting, but it is something you get through,” another discussing “I have had to become very assertive and independent and that has been very hard because my husband did everything for me.”

Two other role changes mentioned by individuals which they felt influenced their grieving was the need to “become the handyman,” and the adjustment of adult sons to recognise a mother as “leader of the family affairs...I think they find that hard to adjust.” A third adjustment discussed was that made from having an active sex life to none at all, the future prospects not looking to change due to

religious beliefs and respect for his children, however expressing his torment by saying, "I find myself terribly deprived in that respect...it is a problem and you can not just walk away from it."

INTERPRETATION: All participants were questioned as to the influence the death of their loved one had had on the roles in their life, and if this had changed during bereavement. Changes to their social lives particularly affected the three younger participants who had lost partners. They spoke of a difficulty in socialisation without the deceased, feeling "out of place." Impacted upon this is the issues discussed earlier of people not knowing what to say, or making inappropriate comments and judgement of how a person should or should not be feeling, behaving and grieving.

Some cultures and societies include the ritual or custom of abstinence from social outings and friendships for a specific period of time. Whilst remaining at home in mourning, often other rituals are performed, including wearing of black or specific prayers spoken. Aries (1975) has traced customs of seclusion back to the Middle Ages. He concluded that the two purposes are to shelter the grief from the public and to prevent the bereaved from forgetting the deceased.

Several participants talked of the increased responsibility with the death of a parent, having to take over roles of care for other family members. DeSpelder & Strickland describe such changes as "the death of a parent forces a person to realise perhaps for the first time, that he or she has become an adult" (1999, p.400). With increased responsibility can come secondary losses, of time and freedoms no longer available. Such death also often symbolises the death of the one person whose love has been unconditional, unique, and irreplaceable (Moss, Moss, Rubinstein & Resch, 1992-3), as one participant stated; "parents are the only ones who can really love you unconditionally, the only ones you can really rely on one hundred percent."

The loss of a partner was found in the data to initiate not only social change, but also secondary changes. Two participants returned to work, one after a long absence from the work force. She went from wife to widow, mother to single parent, housewife to employed. These role changes effect all family members, not just financially, but physically and emotionally as well. How people cope with such drastic role changes depends on socio-cultural, personal, and a host of circumstantial factors (Levy, Martinkowski & Derby, 1994). Supports offered must consider the overall effects of death, not just the obvious loss.

One of the largest role changes, seen both in the data and literature, effected mainly elderly widows who have lived out a life where their husbands took on a traditional role, and thus post death they found they had to learn new skills, including managing financial accounts and becoming “the handyman.” These changes can prove particularly difficult if compounded by ill health, and a perceived lack of training and support. “Learning to manage unfamiliar role responsibilities in the midst of grief can be a formidable task, intensifying feelings of helplessness” (DeSpelder & Strickland, 1999, p.405).

Particular roles which are lost are also of significance. When a person dies, the roles obviously change. Amongst these are those of a husband, wife, partner, or lover. When planning bereavement support, it is essential these important roles are not avoided in conversation due to embarrassment of talking about sex and intimacy with a stranger. Grief “involves re-establishing physical and mental balance so that the bereaved can get on with a life that is irrevocably changed, but still worth living” (DeSpelder & Strickland, 1999, p.240).

4.7 STORY TELLING

4.7.1 Continuing Bond

ANALYSIS: Four participants discussed the importance of talking about the deceased in a mixture of formal and informal ways. One took comfort in the idea of talking or story telling in a group setting, her interpretation of such therapy being “it kind of makes you remember the person more. Even though you might be unhappy at the time, it is sort of a nice unhappiness...it is nice to remember them.” Others encouraged family and friends to talk about the deceased stating, “I like to talk a lot about (the deceased), that really helps me...I do not speak about the sad things,” and “I think if it is talked about more it would help.”

Fourteen out of the fifteen participants discussed their grief from the point of view that it was not a process that will end, but rather as continuous and life altering. Over a third felt the deceased could never be replaced, expressing feelings in ways including “you never get over it, but you learn to deal with it...you still think about them, you get sad about them,” and “when you have been married forty-eight years you do not give that person up. They are always there, no matter where you are, no matter what time of day or night.” One person expressed frustration with others expectations that grief is time limited or ending stating, “someone said after three years you have picked up the pieces again. You never forget the person you have lost...you never forget, so why?” Another experienced similar expectations and expressed, “I do not think there is any right or wrong. We lost our daughter fifteen years ago and that is still there as if it was yesterday. Grieving is a strange thing.”

A presence felt or a visit from the deceased was mentioned by a fifth of the participants, giving them a further sense of relationship with the deceased. “I wake up in the morning and sort of feel he is still there,” with another stating “he has come back to me twice.” All who experienced this found it a comfort. One participant reports contacting her spirit guide through her spiritualist church, initially being upset it was her grandmother and not her deceased father, saying, “I was expecting my dad, I wanted him,” but was nevertheless convinced that this

contact would occur at a later date. For another, the waking of his dying partner from a semi conscious condition to state clearly “I know where I am going and it is good - they have come,” offered him great comfort in his grieving.

INTERPRETATION: In the literature review (see section 2.9, page 48), and the interpretation of ‘Creative Expression’ (section 4.2.1, page 89), the importance of story telling is explored in depth. Thus, this section of interpretation will not repeat the same, however instead it will explore what importance story telling had in the data. Much of the interview, both in style and content, was designed so that participants felt encouraged to tell their story. A main theme evolving from the data was people’s need to tell that the story does not end with death, but rather the relationship develops and changes over time. Fourteen out of fifteen stated their opinion that the process is not only life altering, but is continuous and lifelong.

Therefore the ideals evolving in the New Paradigm of grief theory and literature were found throughout the data in over ninety percent of cases, primarily that grief is not a finite process. “As the knowledge base concerning bereavement has expanded...the notion of ‘standard duration’ of grief has largely been put aside” (DeSpelder & Strickland, 1999, p.241). A third of the participants discussed the idea that they would never replace or forget the deceased, paving the way for a continuous relationship. One person in fact was quite angered by the traditional notion, particularly within her cultural reality, that a person should achieve closure within a certain time and expect an ending to grief.

Four participants continued the relationship with the deceased by finding time and place to talk to them, a behaviour which may have once been considered pathological. Hopefully this indicates that people are becoming more aware of the importance of keeping a healthy and lifelong relationship with the deceased, and not feeling threatened by others if their opinions differ.

Participants in the data noted the importance of talking about the deceased; another way of keeping a healthy relationship alive with them. This could be achieved in formal and informal settings, with bereavement support, needing to recognise the importance of such, and provide adequate rooms for this therapeutic story telling. The bereaved “come to bring us their stories. They hope they can tell them well enough so that we understand the truth of their lives” (Coles, 1989, p.7).

Another way the participants continued a relationship with the deceased, reported by three interviewees, was by ‘visits’ from the loved one after death. This is documented in the literature, with one study finding that “53% (n=50) of the subjects stated that they felt the presence of their loved one” (Longman, Lindstrom & Clark, 1989, p.34).

4.7.2 Telling of the Illness

ANALYSIS: During the interviews thirteen out of fifteen participants discussed their loved one’s illness and demise, often in great detail. Several participants recalled the illness in lengthy monologues, intertwined with other themes including criticism of the hospitals or doctors, process of diagnosis and disease, and issue or symptoms faced at the time of deterioration.

INTERPRETATION: Most participants, during the interview, discussed the deceased’s illness. At times this was to give background information and provide greater understanding of answers given, however often it became a dominant part of the story. Included often was the diagnosis, illness, nursing stages and death, several times causing emotional reactions by the bereaved, such as crying.

At first, it was thought by the interviewer that the purpose of the visit and interview was not clear; perhaps the participant thought it was to review the nursing program rather than the bereavement support. This confusion may have been worsened by the fact that the interviewer was a nurse from the community team. However as the data continued to unfold it was realised that participants had a need to tell this part of their story. It may be a part of their story that, through discussion, brings the deceased nearer. They may also reveal hidden frustrations or anger, which will be voiced and heard only in the telling. This is most probably a story that only select people hear, as friends and family may have experienced and therefore may not be willing to listen to it again. Thus it may not be told as often as the bereaved may like. As Younger states, these are “stories of our search through the ages for truth, for meaning, for significance. We all need to tell our story to understand our story”. (1995, p.67). This has important ramifications for bereavement therapy, especially in relation to the encouragement of group work and counselling.

It was also found in the data that over two thirds of participants discussed the life they had with the deceased before illness and death. This was often to give background information to help the interviewer understand the importance of the relationship, and the significance of the deceased in the bereaved’s life.

4.7.3 Other Deaths

ANALYSIS: Nine participants discussed previous deaths mourned, sometimes comparing and contrasting the grief experienced. Some talked of further recent deaths. However most of the deaths discussed, apart from the person they cared for on the home nursing program, were several years previous, up to fifteen, and were discussed in some detail.

INTERPRETATION: The phenomenon of grief recurrence is not new. It is discussed throughout the literature and recognised by some as a risk category, with Rosenblatt stating, “the fresh grief...may often be entangled in grief for other losses, and quite possibly, each recurrence of grief for one loss may set off grief for other losses” (Rosenblatt, 1996, p.45). Thus, it is not surprising that so many of the participants discussed other deaths which had affected their lives through the interview.

One major implication which this has is that it indicates an ongoing relationship, or continuing bond, with the deceased. It is not a finite process, which is completed within a certain time frame, but a lifelong process. “One implication of grief recurrence is that after one’s first major loss, one will never be completely free of grieving” (Rosenblatt, 1996, p.54). This is not necessarily a negative idea, as the new relationship with the deceased can be a very positive and fruitful one. This recurrence of grief is important to remember when planning bereavement care, both to recognise and pre-empt possible hard times, and be willing to explore loss with the influence of previous losses in mind.

4.8 AGE RELATED INFLUENCES

A strong theme emerging in literature and theory is the presumption that age influences the way a person grieves. However as people develop at different rates their understanding of death is influenced by other human traits, not necessarily chronological age (DeSpelder & Strickland, 1999). Society places expectations upon the bereaved in relation to what they think the impact of the grief should be, falling into stereotypical ideas that it is more tragic to lose a child than an elderly parent. “Of all the losses that can be experienced during adult life, most feel that the death of a child is the most painful” (1999, p.384).

This was found in one interview where the participant told of other deaths, particularly reminiscing about the death of her granddaughter through sudden infant death syndrome. Another told of the pain still felt fifteen years after the death of her daughter. One participant, however, disagreed with this theory, expressing the tragedy of losing your partner of many years, "I think probably the older you are the longer relations you have had, it is more difficult to cope with."

Part of this study aimed to explore the relationship between age and grief, by choosing participants according to age groups to achieve an even spread from twenty to ninety years. Overall the age of the participants did not appear to have a large impact on the grief process, however it is difficult to determine when so many other factors can influence these findings, and also considering the sample size. An example of other influences is the type of relationship between the bereaved and the deceased. The majority of younger participants lost a parent as opposed to the older group who had mainly had their partner die. The older population are also more likely to have pre-existing medical conditions and poorer health, which may also influence these outcomes.

The main areas where the age of the participant influences the grieving process was seen and discussed in the 'Anger' section (4.1.5, page 78), with the younger members discussing it more often.

The elderly participants were more likely to attend community groups. This is most likely to be due to the activities offered and time availability for the participant, a concept further explored in section 4.3.6 (page 111).

One bereaved participant discussed in the interview that her children do not choose to discuss the death of their father, yet the grandchildren do. This was however the only such distinction found, with all other participants willing to tell their grief story, mostly in great detail. The last major influence found in the relationship between age and grief was that the elderly tended to experience

greater role changes, as discussed further in the interpretation of section 4.6 (page 136). These role changes were particularly observed with elderly widows needing to learn new skills.

4.9 PARTICIPANT'S RECOMMENDATIONS

Thirteen of the fifteen participants made recommendations as to how to support the bereaved by improving services in the community. As mentioned in the 'Bureaucracy' section (page 117), several people experienced difficulties with banks and government departments. Most complaints and suggestions arose as a result of a feeling of dissatisfaction over the handling of their situation by staff. Six participants recommend further training be given to staff in what most labelled the "P.R" area, for example how to deal with bereaved customers, and where to send or transfer them to have their queries answered; "Tellers should be trained in how to deal with these situations." Efficiency in paperwork and computer programs, particularly concerning the changed labelling of correspondence from government departments, was felt to need more internal education.

Several participants suggested that nursing, hospital and medical staff should be made aware of these bureaucratic difficulties in order to alert patients and their relatives of potential problems they may face. The recommendations extended to staff alerting clients to such matters as Power of Attorney ending at death, the need for Statutory declarations, picking up of the ashes and the possible fees and taxes involved with transfer and paperwork. A few recommended holding off the paperwork, such as closing accounts and changing titles, for a few months until the bereaved is "not so vulnerable."

From a different perspective one widow considered the pre-arranging of the funeral as “one of the best things we could have done...I think that took a great deal of pressure off.” Two participants recommended that nurses and staff encourage patients and families to make the most of opportunities to achieve goals whilst still able to do so, even if they are diagnosed as terminally ill.

Another felt it would be appropriate to offer four to six weeks compassionate leave; “like maternity leave, so you can make the most of the time together whilst well and come to terms with things.”

Further education for nursing and medical staff, with regards to availability of grief literature and services within the community, was suggested. Two participants recommended that general practitioners, hospitals and communities be more aware of the services available to the terminally ill, referrals be made earlier, and doctors and nursing staff be educated “to listen and to be there for them.” Two stressed that honesty from the staff, particularly medical, was paramount when dealing with patients and relatives.

Two participants suggested that nursing staff should encourage the use and emphasise the importance of the hospital’s Carer Education Program, “because you flounder a little bit in the dark.” One felt support of the family would be increased if the nurses continued to visit after the death, while another recommended the organization’s staff facilitate a family meeting, post death. This would be to explore any issues of unresolved anger; “some counselling afterwards as a group about the tension that can happen, and the grievances between each other.”

One in five participants believed that support groups would be beneficial in order to allow the bereaved to relate their stories, “with someone who has been through it and is positive in attitude” to facilitate.

Two others recommended joining community groups, while another felt that schools needed to increase their understanding and the supports they offered.

Another person discussed the negative stigma surrounding the words, "Palliative Care," suggesting it be changed to "Special Care" to avoid the poor connections; "I think it would be better because palliative means final stages."

The final two recommendations made were in regards to information exchange. One was to provide a tape or CD Rom to educate patients and their significant others with information usually given at the hospital by staff, who are "interrupted and extremely busy." It was felt that, because of the emotional reactions at the time, including shock and denial, little is taken in. A videotape or CD Rom explaining the basic effect and reactions to, for example, chemotherapy and steroids, and what precautions are available would help provide patients and relatives with the means to listen and absorb information at their convenience, and when they are emotionally ready. The second was of the same nature with the information pertaining to the last stages of the disease process, what to do when the person dies, how to dispose of medication and warnings about possible problems likely to be faced.

Chapter Five

5.1 CONCLUSIONS

Grief and loss is an experience common to all human existence. Traditional theorists of the twentieth century explored grief in a number of ways, both as a process and a disease. This line of thought changed in the latter part of that century with stage theories developing to complement the growing popularity of the hospice movement. Recent evidence, which has challenged preconceived ideas and assumptions regarding bereavement, has emerged providing society with a new paradigm. This new wave of thought provides recognition that bereavement, rather than being sequential, time limited and predictable, is in fact oscillatory, continuous and highly individual.

Another dominant theme to emerge from the new paradigm, along with grief being recognised as an individual process, is the encouragement to allow the construction of a continuing bond with the deceased. However it is important to recognise the significance of role changes that occur due to the loss. Incorporated in this is the healing relationship with the deceased. This may involve re-establishing a balance so as to continue with a life that is still worth living, but which is irredeemably changed.

The data shows that grief is expressed by a diversity of emotions and behaviours. Although it is found that several of these are common to many, and thus predictable to some extent, it is also recognised that, due to the individual nature of grief, particular expressions seen by the bereaved should not be anticipated. Expectations of how the bereaved should or will behave must be put aside, adopting instead a more accepting, flexible, and unique viewpoint. A

viewpoint which allows for, and respects, individual creative responses to be acceptable and encouraged.

The comforts and supports sought during grief are specific and unique to each person. The importance of rituals and spirituality in the grief process is emphasised, such as visiting a cemetery, memorial park or garden. The narrative or story telling as an emerging topic tells of the value of self exploration and expression, allowing for diversity of need, meaning and significance. Other modes of creative expression found to be important as a cathartic experience included meditation, gardening, artwork, and various physical activities.

The originality of expressions, comforts, and supports has a direct bearing on the offering of bereavement programs. It is evident that bereavement care is a necessary, appreciated, and successful component of holistic care. However to ensure further success there must be flexibility, creativity, and careful planning. Recognised is the concept that only a small percentage of the bereaved will access support from such services, therefore there must be guidelines to alert palliative care workers as to who is most appropriate to receive the support.

Bereavement support in general received mostly positive feedback, however the study did illuminate areas in society where the bereaved were less than satisfied. These revolved around bureaucracies, such as banks, government agencies and hospitals. Inappropriate comments from family and friends frequently proved hurtful. More education is needed for employees of institutions who deal with the bereaved, so that these dealings may be conducted in a helpful and compassionate manner. Whether this negativity and inappropriateness comes from ignorance in dealing with the situation, lack of understanding, or a less caring and more economically driven approach, it is evident that this dissatisfaction is occurring on too regular a basis and caused pain, upset, and unnecessary stress to the bereaved in this study.

Health professionals are viewed as educators and information providers to their patients, and also the families and friends of the patient. These professionals must therefore be up to date in skills and knowledge concerning the grief process. They must be able to establish rapport and impart information to others in a compassionate and non-judgmental way. The information would include a variety of areas, ranging from education in physical care and symptom control, through to encouraging the family and friends to make the most of the time together.

Ideas and beliefs surrounding grief and bereavement support have developed extensively, particularly in the past forty years. Through the development of a new post modern paradigm, society has the potential to take care and support to new levels. Compassion and understanding are key elements, allowing for individual expression, a continued and ongoing relationship with the deceased, no time limit expectations, and the implementation of appropriate, well planned bereavement support programs.

5.2 RECOMMENDATIONS

Recommendations are made on the basis of respondent's perceptions of the grief process and the bereavement support received in the community.

1. There is a need for grief to be recognised as an individual process, which is neither sequential nor time limited, but diverse and unique. The recognition of this needs to be encouraged through the education of all care workers in the palliative care and bereavement areas, and society in general.
2. The concept of a continuing bond and lifelong relationship with the deceased as a healthy and important one needs to be further explored. This is an idea which is contradictory to the writings of many theorists whose work may still

influence current beliefs and protocol in bereavement care. Therefore the ideas of the new paradigm need to be further discussed and explored.

3. Care provided during the illness, dying and bereavement phases must offer flexibility and respect for uniqueness, as well as encouraging independence, providing education and empowerment, and teaching coping strategies to the dying and the bereaved.
4. There is a need for greater understanding through provision of education for health care workers in the area of palliative care and bereavement, with particular focus on communication skills and counselling techniques
5. It is essential for carers and health workers to encourage patients and their family and friends to set achievable hopes and goals, making the most of the limited time they share.
6. Where appropriate, it is important for staff to encourage carers to stay involved with community groups. The care team requires a good working knowledge of these programs and methods of referral.
7. General knowledge of supports available, and appropriate methods of referral, is needed by care workers to utilise optimum assistance.
8. Hospitals and health professionals could revise ways to better utilise time spent with the patient and their significant others, in view of the current economic funding and staffing levels. This would assist in providing not just task orientated care, but holistic support, which helps recognise the vitality of story telling, unique expression and spirituality.
9. Means of education and delivery of information to prepare the patient and their significant others, especially by medical staff, need to be reviewed.

Because of the combination of increasing limited time, coupled with the advancement in information technology, other tools and instruments, taking this technology into account, need to be explored.

10. There is a need to teach care staff about the possible difficulties the bereaved may face when dealing with bureaucratic agencies. Care staff would then be in a position to educate patients and their significant others about these potential problem areas, and in some circumstances act as advocates.
11. A wide variety of components is necessary in the planning and implementation of bereavement follow up support programs, in order to offer a creative and flexible approach to suit a diverse group of grieving individuals. Effective preparation and inclusion of policy and protocols is necessary, as well as the execution of regular evaluation and review of these programs.
12. Organisations that deal with the public, for example banks, need to review the current level of education given to staff, to better prepare them in their dealings with bereaved clients. Education and understanding needs to be increased, particularly in the areas of appropriate procedures, knowledge of departments to which the bereaved should be referred, and public relation and communication skills.
13. Bureaucratic organisations, including banks and government departments, need to examine their current policies and procedures when dealing with bereaved clientele. Fee structures concerning the changing of titles and accounts need to be considered, as does the efficiency of procedures relating to official records and correspondence after the person has died.

14. Greater variety is needed when assessing 'at risk' behaviours of the bereaved. Rather than the focus being placed upon 'at risk' behaviours, there is a need to explore the implications of resilience factors. This concept needs further research and exploration, both at theoretical and practical level.
15. There is a need for further research in the area of grief and bereavement support. Of particular importance is exploration of the emerging paradigm, and its impacts on practice. This paradigm provides the opportunity to generate new hypotheses and theories in the area.

5.3 SUMMARY

One of the aims of this study was to obtain in depth knowledge of the grieving process, achieved partly by a review of the grief literature, and in particular the theories of the last one hundred years. Data from interviews of bereaved participants is also analysed to further the knowledge and understanding of grief and bereavement.

The Literature Review begins with the classic work of Freud (1917), and follows the development of grief theory through the Twentieth Century. A new wave of thought, which emerged in the last part of the century, changed the emphasis of grief work from the time limited, predictable and linear process to an oscillating and individual experience. This new paradigm encouraged a continual bond with the deceased. How these new developments effect the process of grief and bereavement supports offered is explored.

Bereavement programs are reviewed in the literature, exploring the different types, advantages and disadvantages. Data regarding bereavement support

programs offered in our community are analysed from the interviews, further exploring the concept of bereavement follow up.

The analysis of the interviews explored expressions found to be similar throughout the experiences of the grieving participants, as well as reviewing what they found to be of assistance. These included both supports offered from external sources, and on a more personal level which media and actions bought comfort to the bereaved. Issues which the participants found problematic whilst grieving were reviewed, along with other common themes that emerged in the data, including spirituality, coping with role changes, the importance of story telling, and the influence the participants' age has on the grief process.

Recommendations are made, both by the author and separately by the participants.

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APPENDIX 1

Interview Questions

1. How are you managing in general after the death of?
2. What are the main influences the death has had on your life?
3. Has it influenced your social life in any way?
4. Has it changed your family life, or changed the roles you have; either in the family or in general?
5. What do you find are the most difficult times for you?
6. Has it influenced your health in any way? How have you been sleeping/eating over the last twelve months? Have you had more flues/illnesses than usual?
7. Has it influenced your spiritual beliefs in any way?
8. What were the main sources of supports you received?
9. What were the most beneficial, and were they adequate?
10. What ways could we improve the supports our community offers people who are bereaved?
11. What things gave you comfort at this time?

12. Did you have to deal with any government institutions / bureaucracies (i.e. Banks), after the death and how did you find these?
13. Bethlehem follow up bereavement program followed you up, probably by sending letters and/or phone calls, or personal visits. How did you find their support?
14. Are there any suggestions you have for us to improve this program?
15. Are there any suggestions / recommendations you could pass on to anyone about to go through what you've been through in the last twelve months?



APPENDIX 2

AUSTRALIAN CATHOLIC UNIVERSITY

REVIEW OF THE GRIEVING PROCESS AND FOLLOW UP BEREAVEMENT PROGRAMMES

RESEARCHER: CATH TOMLINSON

SUPERVISOR: MICHAEL GROOME

My name is Cath Tomlinson, and I am presently a postgraduate student at Australian Catholic University and employed as a nurse with Bethlehem Hospital's Community Palliative Care Service. I am researching the process people go through whilst grieving, and what supports are available to them within our community. Specifically I wish to review the Community Palliative Care Service's Bereavement Program offered by Bethlehem Hospital.

As your family member/friend was nursed by the Bethlehem Community Palliative Care Service, and you are presently on the Bereavement Program, your information and opinions are most important to the research.

If you feel comfortable in talking about your grief and your perceptions of our Bereavement Program I would like to conduct an informal interview of about 45min-1hr duration, at a time and place convenient to you. For data collection reasons this interview will be audiotaped and fully transcribed, and all efforts will be made to ensure confidentiality. My supervisor and I will be the only people with access to the tapes and data. They will have no identifying details, as I will be using pseudonyms instead of names.

If you choose not to participate it will in no way influence the continued follow-up support that Bethlehem offers you.

This research proposes to gather in-depth information to better understand grief and loss, and thus has the potential to improve our personal care, and our community support to those who may be in need. Its aim is also to review our current support program and adapt it where necessary to meet its participants' needs.

The results will be fed back to the Bethlehem Hospital's Bereavement Program staff by the researcher with the view to improve the service, and may be

published in a Palliative Care nursing journal. No individual information will be used.

Only a certain number of participants will be interviewed, due to financial and time constraints. If you are not selected you will be notified by mail, and will be able to obtain the results of the study once complete. Please notify the researcher on 9595 3330 if you wish to obtain the results, even if you are not selected for an interview.

If selected you are free to withdraw consent and to discontinue participation in the study at any time without giving a reason. Withdrawal will not influence your follow-up bereavement care.

Any questions regarding this project can be directed to Michael Groome (research supervisor) on 9241 4578, or Mark Cockayne (Coordinator, Bethlehem Community Palliative Care Service) on 9595 3330. If you wish for any counselling or follow up after the interview please contact the Bethlehem Hospital Bereavement Program staff on 9595 3330.

The University Research Projects Ethics Committee at Australian Catholic University and the Research and Ethics Committee at Bethlehem Hospital have approved this study.

In the event that you have any complaint about the way you have been treated during the study, or a query that the Researcher has not been able to satisfy, you may write care of:

**Chair, University Research Projects Ethics Committee
C/o Office of Research
Australian Catholic University
412 Mt. Alexander Road
Ascot Vale VIC 3032
Tel: 03 9241 4513 Fax: 03 924 4529**

Any complaint made will be treated in confidence, fully investigated and the participant informed of the outcome.

If you agree to participate in this project you should sign both copies of the Informed Consent, retain one copy for your records and return the other copy to the Researcher.

Yours sincerely,


Cath Tomlinson

APPENDIX 4

10 April 2000

Cath Tomlinson
Community Palliative Care Service
Bethlehem Hospital
476 Kooyong Road
CAULFIELD VIC
PH: 03 9595 3330

BREAVEMENT RESEARCH

Dear Sir / Madam

Thank you for your willingness to participate in the research project regarding the Bethlehem Community Palliative Care Service bereavement follow-up program. Due to the nature of the study, time and financial considerations, only fifteen people will be interviewed. These people were randomly selected and your letter was not included, thus you will not be required for interview.

I greatly appreciate your support in this matter and if you would like to receive a copy of the results once published, or have any further suggestions to add to the program, please contact me on the above phone number.

Yours sincerely



Cath Tomlinson

**REGISTERED NURSE
BETHLEHEM CPCS**



APPENDIX 5

AUSTRALIAN CATHOLIC UNIVERSITY

Office of Research
University Research Projects Ethics Committee
Ethics Clearance for a Research Project - Approval Form

Investigator(s)/Supervisor:	1) Mr Michael Groome	Campus: Mercy
Researcher (if student)	2) Ms Cath Tomlinson	Campus: Mercy

Ethics clearance has been provisionally granted for the following project:
A study of the grief process and evaluation of a follow-up bereavement programme
for the period: 7/7/99 to 30/11/00
University Research Ethics Committee Register Number: V99 - 47

subject to the following conditions as stipulated in the National Health and Medical Research Council (NHMRC) Statement on Human Experimentation and Supplementary Notes 1992:

- (i) *that principal investigators provide reports annually on the form supplied by the Institutional Research Project Ethics Committee, on matters including:*
 - *security of records;*
 - *compliance with approved consent procedures and documentation;*
 - *compliance with special conditions, and*
- (ii) *as a condition of approval of the research protocol, require that investigators report immediately anything which might affect ethical acceptance of the protocol, including:*
 - *adverse effects on participants;*
 - *proposed changes in the protocol, and/or*
 - *unforeseen events that might affect continued ethical acceptability of the project*

and subject to the following conditions as stipulated by the University Research Projects Ethics Committee:

- Security of Data: [Section 5.2 (a)]
 - State that data will be stored on University premises during the study
- External Approvals:
 - Please forward Ethics Approval from Bethlehem Hospital to this Office when received
- Maintenance of Anonymity: [Section 6.1, page 9 of 13]
 - It may be difficult to maintain anonymity since the researcher works at the hospital and will be conducting face-to-face interviews. Either explain further how it will be maintained or tick the NO box in 6.1(a)
- Information Letter:
 - Please rectify linguistic inaccuracies as indicated

An Annual Progress Report Form will need to be completed and submitted to the URPEC within one month of anniversary date of approval.

Please sign, date and return this form (with any additional information or material, if requested by the Committee) to the local Administrative Officer (Research) to whom you submitted your application for approval to be confirmed.

Signed: Gay Filby
URPEC Administrative Officer (Research)

Date: 14/7/99

(To be completed by the Principal Investigator or Supervisor and Student, as appropriate)

The date when I/we expect to commence contact with human participants or access their records is: 23/8/99

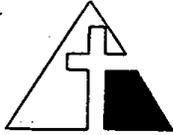
I/We hereby declare that I/We am/are aware of the conditions governing research involving human participants as set out in the Research Projects Ethics Committee's *Guidelines and Instructions for Researchers/Students* and agree to the conditions stated above.

Signed: [Signature]
[Principal Investigator (if staff) or Supervisor, as appropriate]

Date: 20/7/99

Signed: [Signature]
(Researcher (if student))

Date: 20/7/99



BETHLEHEM HOSPITAL INC.
THE SISTERS OF THE LITTLE COMPANY OF MARY

476 KOOYONG ROAD
CAULFIELD
VICTORIA 3162
Tel: (03) 9596 2853
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Registered No. A0011233X

APPENDIX 6
6 December 1999

Ms Cath Tomlinson
Bethlehem Hospital
Community Palliative Care Service
476 Kooyong Road
CAULFIELD VIC 3162

Dear Cath

I am pleased to advise that your proposal for the conduct of your study titled, "*A study of the grief process and evaluation of community bereavement program*" has been granted ethical approval by Bethlehem Hospital.

Please note that for future correspondence purposes the relevant reference number to be quoted is -

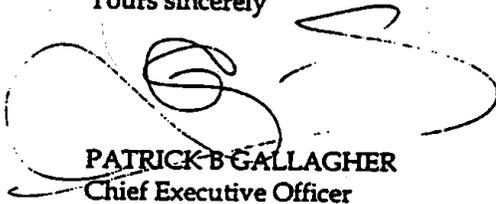
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In addition please note the following standard conditions that apply when such ethics approval has been granted by Bethlehem Hospital -

1. ethical approval is granted for a two year period effective from 2 December 1999
2. immediate notification to Bethlehem Hospital's Research & Ethics Sub-Committee of any adverse affects on human subjects
3. in the reporting of all adverse events, the Chief Investigator shall be required to explain in their opinion the significance of the event(s) being reported
3. the immediate notification to Bethlehem Hospital Research & Ethics Sub-Committee of any unforeseen events that may affect the continuing ethical acceptability of the project
4. approval to be sought from Bethlehem Hospital's Research & Ethics Sub-Committee of any proposed modifications to the project, and

5. submission of report at the completion of the project, with an interim report being provided at the expiration of the first 12 months and each 12 month period thereafter should the study be in excess of one year's duration.

Yours sincerely



PATRICK B GALLAGHER
Chief Executive Officer

PBG:ml