Storying Meaning in Hospice Patient Biographies

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He who has a why to live can bear with almost any how

(Nietzsche, cited in Frankl, 1964)

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ABSTRACT

The importance of meaning in life has been emphasised in the writings of many existentialists. Furthermore, serious repercussions have been associated with loss of meaning. Postulated life-enhancing qualities of discovering meaning in life make this an especially critical issue for the dying. A sense of meaning in late-stage disease is an important focus for therapeutic exchange. A notable method which has been shown to facilitate this is the production of a life story (Lewis, 1989). Narrative is a natural instrument which facilitates expression of personal meaning. Engaging in storying life clarifies meaning of experience by affording closure (Lashley, 1993).

The present study employed narrative inquiry, a subset of qualitative research designs, to examine hospice patient biographies (N=7) to determine how the process of constructing a biographical account facing death contributes to meaning formation. It has been argued that approaching death disrupts one's personal narrative resulting in loss of meaning. This activity is said to compel reconstruction of one's story in order to restore meaning in life. Lichter, Mooney and Boyd (1993) argued that recounting experiences enables individuals to resolve unfinished business, an important element for promoting closure, which engenders meaning.

Two methods of analysis were adopted: analysis of narrative and storying meaning. Analysis of narrative was based on Polkinghorne's (1995) methods of narrative configuration. Storying meaning was carried out as a means of making sense and showing the significance of thoughts and actions in the context of an unfolding plot.

With analysis of narrative a variety of inquiries were undertaken. This included examining the biographies for narrative typologies. Given the importance of goals in meaning formation, we focused on the plot structure before and after illness to establish the influence this experience had upon goal direction. Narrative devices which contribute to meaning formation were also explored. This included: roles, epiphany, closure, and metaphor. These features were examined for patterns, themes, and regularities across biographies. Considering the detrimental impact death anxiety has upon meaning construction, inquiry also focused on this concept and its association with selected narrative devices.

With storying meaning, knowledge about a particular situation is produced. In this study we concentrated on how meaning is constructed through storying a life facing death. This encompassed searching for processes of meaning-making within the biographies.

Analysis of narrative revealed goal-focused progressive narratives. Storying lives in this coherent fashion enabled meaning to be constructed. Narrative devices assisted in production of a coherent story which promoted closure to storied life. Adoption of these devices also positively reframed the narrator's viewpoint toward this experience, which enabled individuals to make sense of events and happenings in the story. Surprisingly, death anxiety assumed a peripheral concern; it did not feature as a critical issue in meaning construction within these accounts.

Storying meaning revealed processes of meaning-making in these storied accounts. Unfolding of these stories revealed meaningful lives interrupted by adversity, which were then overcome. Prior to the disruption these accounts were replete with sources of personal meaning. Disruption ensued with evidence of loss of meaning. Restoring meaning involved reconstructing one's personal narrative. Analysis revealed evidence of processes of meaning-making within these stories. Methods of meaning formation included: making sense of illness, changing the life scheme, changing one's perception of the event, and methods of self-transcendence. Similar processes have been established in other studies examining meaning construction. These processes were found to promote closure in storied accounts, an important element which facilitates meaning. This finding supports Lichter and associates' (1993) argument regarding the value of narrative, particularly for those facing death where meaning in life has been lost.

Results indicated individuals construct meaning by reconstructing personal narratives in order to make sense of these experiences and integrate these into their storied lives. As Williams (1984) argued it is in this activity of reconstructing one's personal life narrative that illness and its consequences are ascribed meaning in the context of one's life. The value of narrative for those approaching death and those experiencing serious loss is emphasised.

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INTRODUCTION

"Having been is the kind of being, perhaps the surest kind."
(Frankl, 1965)

The importance of personal meaning in life has been emphasised in the writings of a number of theorists, particularly Victor Frankl. Moreover, they have identified serious repercussions associated with its paucity. Various researchers have found meaning in life to be consistently related to positive health outcomes, while meaninglessness has been associated with pathological results. In particular, considerable empirical work has been devoted to the concept of meaning as it pertains to major life events. Explicitly, investigations into a range of pernicious experiences have highlighted that finding meaning in life's misfortunes may be important in regaining or maintaining mental and physical health. This examination will focus on selective events including major negative life events, illness, the elderly, with a particular emphasis on the terminally-ill.

Meaning in Major Negative Events

Research has demonstrated that individuals often locate meaning and purpose following traumatic events and this has important implications for the way they adjust to these experiences. Many victims of negative events have found meaning by focusing on the positive aspects of their experience rather than on the costs incurred (Thompson, 1985). Similarly, Bulman and Wortman's (1977) study of recently paralysed accident victims, demonstrated locating meaning in this event. Specifically, subjects re-evaluated their situation and concentrated on the positive factors. As Antonovsky's (1987) review of trauma research illustrated, individuals made sense of these events by concentrating on meaningful areas within their life.

Another study that exemplifies this finding is Thompson's (1985) survey of people whose homes were destroyed by fire. She noted more than half of the sample perceived some positive meaning in the experience. Further, five ways of focusing on the positive repercussions of the event were observed. These included: finding side benefits, making social comparisons, imagining worse situations, forgetting the negative, and redefining. Redefining involved rethinking what was desired from the situation; an event was perceived

in a positive manner if one's expectations did not exceed the likely outcome (Rothbaum, Weisz & Snyder, 1982).

In addition, victims have also located meaning in negative life events by establishing purpose in their experience (Thompson & Janigian, 1988). For example, parents who have lost a child may find some meaning in their loss if they perceive their child's treatment contributed to medical knowledge that will help save other children (Chodoff, Friedman & Hamburg, 1964). Other victims of traumatic events frequently felt their experience served some useful purpose, such as improving a marriage (Helmrath & Steinitz, 1978), revealing inner strengths, or heightening an appreciation of life (Mages & Mendelsohn, 1978; Moch, 1989).

More recently, Diehl, Haas and Schaefer's (1994) study examined the importance of meaning for intensive care nursing staff caring for a brain-dead pregnant woman on life support. Meaning was utilised as a way to contend with this experience and was found through recognising a positive purpose, such as: respecting her rights, decreasing painful stimulus, allowing the family to say goodbye, and giving the fetus time to grow.

Empirical research has also illustrated the ability to discover meaning following a traumatic life event is important because it has been established as a significant component of adjustment. To illustrate, Silver, Boon and Stones' (1983) examination of incest victims discovered those who were able to make sense of their victimisation were less psychologically distressed and experienced improved social adjustment. Furthermore, those unable to form a sense of meaning in their experience reported greater intrusive thoughts.

In retrospect, research findings have demonstrated the inherent capacity for locating meaning in life in response to a major life event. These investigations have also indicated that meaning affects the manner in which people adapt to or manage events in their lives.

Meaning in Illness

A number of studies have been conducted which indicate that meaning is constructed in response to illness and influences the manner people respond to these situations (Bulman & Wortman, 1977; Lazarus, 1974; McGuire & Kantor, 1987; Spiritual Care Work Group, 1990; Taylor, 1983). Thompson (1991), for example, found many stroke victims who were able to find meaning in their experience were better adjusted . Furthermore, Thompson and associates (1989) noted that a lack of meaning in life was a predictor of depression in stroke victims, suggesting the importance of personal meaning. Similarly, Nowacek, Anderson, Richards and O'Malley (1986) discovered that the personal meaning of diabetes is an

important element in the daily management of this condition and the psychosocial adjustment to the disease. This finding is more recently reiterated by Nowacek, O'Malley, Anderson and Richards (1990) model of diabetes management which examined the attitudinal element of living with diabetes; self-care behaviours and metabolic control require not only adequate knowledge and skill, but also a positive attitude or a personal meaning toward this experience.

Meaning is especially apparent in serious illness (Fife, 1994), particularly cancer. The search for meaning is documented as particularly prevalent, or intensified among people with recurrent cancer (Cella, Mahon & Donovan, 1990). When an illness of this nature occurs it undermines the routines of daily life and the taken-for-granted assumptions about health that sustain individuals, severing one's sense of predicability and control, and fostering a search for meaning (Becker, 1994).

In addition, the diagnosis of cancer can be particularly threatening as it is associated with fear of pain and death due to the disease and debilitating or disfiguring treatment (Levin, Cleeland & Dar, 1985). Patients also encounter a series of inevitable losses (Frampton, 1989), not only physical health and functional status, but social roles and the activities that contribute to a sense of self-worth, well-being and meaning (Block & Billing, 1994). Further, given the chronicity/acuteness and severity of symptoms are related to psychological outcomes, this is a highly salient topic for cancer sufferers (Chrisman, 1990; Meyer, 1985).

Cancer studies have illustrated both the positive aspects associated with meaning and the detrimental impact resulting from meaning that is vague. To demonstrate, Thompson and Pitts' (1993) chronic cancer study indicated that greater meaningfulness was associated with optimism, fewer irrational beliefs and endorsement of internal goals, even when physical functioning and depression were controlled for. Taylor, Lichtman and associates (1984) documented those who were able to place the experience of a breast cancer diagnosis into a meaningful context adjusted well. More recently, Taylor's (1993) examination of individuals with recurrent cancer discovered an unclear sense of meaning was affiliated with poor adjustment to illness. Interestingly, a sense of meaning was not related to whether a search for meaning was reported, advocating Frankl's position that this experience is an unconscious one.

Acklin and associates (1983) observed a negative correlation between sense of meaning and despair, anger or hostility, and social isolation in cancer patients. Maddi (1967) also claimed the latter proposing that individuals suffering from "existential neurosis" experience alienation from self and society. Boszormenyl-Nagy and Spark (1973) posit that

human beings experience an existential void if they cannot establish meaningful connections with others in order to deal with the basic anxiety of living.

Given the importance of meaning, consideration of its deficiency is also warranted. Yalom's (1980) review of research examining the concept of life meaning concluded a lack of meaning was associated with psychopathology. Moreover, empirical research has exemplified that an inability to locate meaning is affiliated with a variety of clinical phenomena.

Frankl (1978) hypothesised that addiction could be the direct result of a deficit of meaning in one's life: *"Addiction is at least partially to be traced back to the feeling of meaninglessness"* (p. 26). By way of illustration, Newcomb and Harlow (1986) demonstrated that perceived loss of control and meaninglessness in life mediated the relation between uncontrollable stress and substance abuse. Similar findings were noted by Hutzell and Peterson (1966), Klinger (1977) and Padelford (1974). More recently, Nicholson and associates (1994) discovered that drug-abusing subjects exhibited significantly lower levels of meaning in life. Various researchers have also connected alcoholism with loss of meaning in life (Crumbaugh & Carr, 1979; Jacobson, Ritter & Mueller, 1977; Newcomb & Harlow, 1986).

Harlow and associates (1986) also present a pertinent example of the impact of meaning deficiency. Their study revealed that meaninglessness mediated suicide ideation for men. This was also recorded in earlier studies by Lifton (1979) and Linehan, Goldstein, Nielsen, and Chiles and associates (1983) who demonstrated a relationship between loss of meaning and suicidal behaviour. Finally, Reed (1989) found a lack of self-transcendence was identified as one of the major precipitants of psychiatric hospitalisation by patients who had been admitted for treatment of depression.

There appears to be an innate tendency to locate meaning when confronted with illness. The meaning attached to serious illness has a profound impact on one's emotional status, adjustment to illness, and ultimately on the quality of their lives (Fife, 1994). Moreover, research has connected meaninglessness with negative outcomes and clinical psychopathological conditions. Therefore, the manner in which individuals choose to construct the meaning of serious illness has a significant bearing on their well-being (Steeves, 1992).

Meaning for the Elderly

Various empirical studies have emphasised the importance of meaning in life for the elderly. Researchers believe this group are especially threatened by loss of meaning because of the many changes and losses they may be exposed to in later life (Klinger, 1977; Lukas, 1972; Moloney, 1995; Peterson, 1985). However, as Haase (1987) has documented, older age per se is not essential for meaning-making; this study examined chronically-ill adolescents and discovered search for meaning may be stimulated by a pivotal event or crisis at any age.

Meaning in life has been proposed to be intimately linked to the elderly's health. The presence of meaning in life has been positively documented in elderly populations. For example, Zika and Chamberlain's (1992) study demonstrated that meaning in life exhibited a stronger association with positive than with negative psychological well-being dimensions in elderly subjects. More recently, Reker's (1994) study which examined life event stresses in a healthy elderly population, established personal meaning functioned as a stress buffer for psychological well-being but not for physical health. However, Butler's (1988) elderly study indicated that personal meaning also moderates the effects of stress on physical health. Perhaps this inconsistency is due to the participants' high standard of health in the former study masking the impact that loss of meaning has upon physical health. Similarly, Reker, Peacock and Wong's (1987) examination of meaning and well-being associated with aging revealed a strong positive correlation between life purpose and measures of well-being. Baum (1981) and Findlay (1981) also found a significant relationship between purpose in life and physical health status among older persons. This highlights meaning's utility for the psychological and physical well-being of the elderly.

In addition, nursing authors have explored the association between self-transcendence and well-being in the elderly. Reed (1989b) discovered that the presence of self-transcendent views and behaviour was associated with emotional well-being. More recently, Reed (1991) found an absence of depression was connected with transcendent views and behaviours in healthy elderly. Specifically, she found this group nurtured their well-being and mental health by expanding self-boundaries: they used inner reflection, accepted physical limitations, and invested in purposes beyond the self as primary practices of self-transcendence. Particular examples included: sharing one's wisdom or experience with others and accepting death as part of life.

Conversely, a variety of investigations have demonstrated the negative repercussions loss of meaning may have upon their health and well-being. For example, Fisk's (1978)

study established loss of meaning was associated with decline in both mental and physical health status in the elderly. Fisk (1980) also found elderly subjects who had lost meaning in life displayed great difficulty adjusting to the environment of the retirement home. Moreover, Fisk discovered depression, anxiety, and somatisation were associated with loss of meaning, a finding maintained by Crumbaugh (1981) who recorded that loss of meaning was positively related to depression in elderly subjects.

Clearly, the presence of meaning in life has an extensive influence on both the physical and psychological well-being of the elderly. Research has also demonstrated that personal meaning may play a "dual" health-promoting and health-enhancing role in this particular group (Reker, 1994).

Meaning for the Terminally-ill

As meaning is important in the areas of major negative life events, illness and the elderly, focusing on the terminally-ill presumably combines all these previous facets into one particular area. However, it is important to note that not all terminal patients are elderly, but demographically the majority fit within this category.

Explicitly, the postulated life-enhancing properties of discovering meaning or purpose in life make this an especially critical issue for the dying. As Frankl (1969) described, this group often display an "existential frustration", a psychopathological condition created by the perception that an ultimate meaning to one's existence is lacking or has been lost. Empirical oncology research has highlighted the detrimental implications paucity of meaning has upon patient health and well-being. For example, Sham and Wee's (1994) hospice study found those unable to find meaning in the final days of their life, felt worthless and hopeless accompanied by expressions of self-pity. Furthermore, Saunders and Baines (1983) point out that feelings of hopelessness and helplessness have been shown to have adverse effects upon one's condition. More recently, Baines (1990) noted emotional and social problems frequently exacerbate symptoms. Hence, this frustration is likely to aggravate pre-existing conditions and lessen the quality of life remaining.

In contrast, various investigations have demonstrated the positive impact meaning has upon patient health. For example, Lewis' (1982) study on late-stage cancer patients discovered those who perceived their world to have meaning and purpose displayed higher self-esteem, were less anxious and more internally oriented concerning their health. This finding has been confirmed more recently by Lewis (1989) who noted the extent to which advanced cancer patients attributed meaning to their situation was a significant predictor of both higher self-esteem and lower anxiety.

Interestingly, the importance of meaning is also often evident in the accounts of hospice patients and their families who describe transcendent experiences: *"experiences of the whole person that brought them in touch with something that they considered to be greater than, or outside of themselves."* (Steeves & Kahn, 1987, p. 115). Many patients feel this is a significant part of the cancer experience (Coward, 1990; Steeves, 1992; Taylor, 1993) which helps relieve their suffering. This has been supported by hospice nurses who observed those who recounted these types of experiences managed their suffering more successfully (Steeves, 1992).

Moreover, given self-transcendent activity has been associated with increased self-esteem and well-being, this is evidently an important component for the terminally-ill (Steeves & Kahn, 1987). For example, Coward's (1990) study examining women with terminal breast cancer illustrated that self-transcendent experiences were related to increased feelings of self-worth and purpose in life. Explicitly, they recalled reaching out and helping other women with breast cancer, while also being receptive to assistance from others, and accepting circumstances they could not change. A second study using the same population revealed a strong correlation between cognitive and affective well-being and self-transcendence (Coward, 1991). Moch's (1990) terminal breast cancer study also highlighted self-transcendent activities; women noted increased richness of relatedness through expressions of caring, needing to comfort others and feeling closeness to others. More recently, Coward's (1994) AIDS study espoused these findings: emotional well-being was affiliated with finding meaning. Participants described gaining increased self-understanding and connectedness with others, which assisted in locating meaning within the context of their illness. This was achieved by helping others with AIDS, for example, support groups and volunteer education activities (Coward, 1995; Coward & Lewis, 1993). Furthermore, they reported increased quality in their lives through reaching out to others prior to their death in order to make a difference in the world.

Interestingly, Reed's assumption that self-transcendence is related to emotional well-being was supported by the participants' expressions of increased self-worth, inner strength, and joy from their broadened views and behaviours (Coward, 1994).

Specifically, for those diagnosed with cancer, the act of searching for and finding meaning is thought to have an adaptive purpose in that it assists individuals to regain a sense of mastery and well-being over an otherwise chaotic and disordered environment (Bard, 1977). To illustrate, hospice patients who gave meaning or purpose to their situation perceived they had control in their lives (Lewis, Haberman & Wallhagen, 1986). Lewis (1989) also found that a clear sense of meaning in advanced cancer patients was positively

correlated with a sense of personal (versus external) control. Hence, this suggests that derived meaning is a form of cognitive control that protects one's self-concept.

Furthermore, literature infers a positive search for meaning exerts a causal influence upon one's adjustment to this illness (Thompson, 1991). Construction of positive meaning is associated with an ability to continue to obtain pleasure and satisfaction from living (Mechanic, 1977; O'Connor, Wicker & Germino, 1990). This may account for the resolve and acceptance observed in some patients experiencing late-stage disease (Lewis, 1989). In addition, Barkwell's (1991) terminal cancer study illustrated that individuals who ascribed a positive meaning to their pain - seeing it as a challenge, demonstrated lower levels of depression and greater management of pain. Similarly, Weisman and Worden (1976) suggested cancer patients who were able to find something favourable in their illness were least distressed by their condition. Presumably not all individuals construct positive meaning from their cancer experience, but when they do better adjustment is predicted (Taylor, 1983).

In sum, it is indubitable that the construction of meaning is a central aspect of adaptation to terminal illness (Cantor, 1978; Simonton, Matthews-Simonton & Creighton, 1978; Siegel, 1990, 1986). Self-transcendence has been strongly correlated with perceived illness distress and both cognitive and affective well-being, a finding that further supports the emerging value of this construct (Coward, 1991).

Death anxiety and well-being are significant issues within the purview of terminal illness. Both contribute to quality of life and are simultaneously influenced by personal meaning. Examination of these factors therefore appears important.

Death Anxiety

> "A fear of a very inexplicable unknown, the fear of something which can never be known."
> *(Paul Tillich, p.7, cited in Barker, 1968)*

Confronting mortality not only installs a proclivity to search for meaning but can also create death anxiety (Carter, 1993). Anxiety about death is a basic human concern which is putatively heightened for those facing death (Rappaport, Fossler, Boss & Gilden, 1993; Sham, 1994), evidenced in oncology literature. For example, Carter's (1993) study of long-term cancer survivors found encountering mortality created high levels of anxiety. Samarel, Fawcett and Tulman (1997) also discovered treatment for early-stage breast cancer subjects experienced emotional responses such as death anxiety, depression and confusion.

The occurrence of distress is found to originate from the patient's realisation that death is more imminent than previously thought (Taylor, 1993). Further, it is proposed this

arises from the uncertainty and fear surrounding the process of dying and how it will be handled (Block & Billings, 1994). For example, Revenson and associates (1983) noted many of the stresses reported by cancer patients involved issues of existential plight, including uncertainty about the future, anxiety about death and disability. More recently, Carter (1993), Sham and Wee (1994) found most informants were not afraid of death per se, but of experiencing a lingering death and being a burden to others. Kahn and Steeves (1995) also notes that individuals are often afraid of leaving significant others, concerned about how they will manage.

Approaching death, according to Erikson (1963) compels individuals to face the developmental crisis of integrity versus despair, and to prepare for the inevitable end. This triggers the life review process in which the individual re-evaluates the past and attempts to integrate their entire life into a meaningful whole (Butler, 1963; Frampton, 1989). As Lifton (1964) stated candidly: *"death is a test of the meaning of life, of the symbolic integrity - the cohesion and significance - of the life one has been living"* (p. 204). A positive resolution involves a sense of fulfilment, peace, and integrity, rather than a sense of failure, horror, and despair. Carter's (1993) subjects came to terms with their experience through acceptance and integration. However, integrity is not always achieved; when past conflicts remain unresolved and disagreements unreconciled, personal meaning and death acceptance may be difficult to achieve (Erikson, 1963).

Adjunct to this claim, is that fear of death originates from the failure to locate personal meaning in one's life and death (Neimeyer, 1994; Preble, 1992). As Butler (1975) proposed, it is not so much the awareness of our finitude, as our failure to lead meaningful lives which creates death anxiety. Consequently, individuals who perceive their lives as fulfilling and meaningful should display less death fear and more death acceptance (Lewis & Butler, 1974). For example, Quinn and Reznikoff (1985) reported that elderly individuals who lacked a sense of purpose and direction in their lives reported high levels of death anxiety. Similarly, Rappaport and associates (1993) demonstrated that life purpose and death anxiety were inversely related among their elderly population. Durlak (1973) also found a significant negative correlation between purpose in life and fear of death among retirement home residents. Finally, Robinson and Wood (1984) revealed an important relationship between locating meaning in life and death and an accepting orientation toward death: higher levels of discovered meaning were associated with reduced death anxiety and fear of death.

In addition, studies examining the relationship between life review and death attitudes buttress this view. To demonstrate, Flint (1983) found a notable correlation between subjective satisfaction with one's past life and death acceptance. Furthermore, Wong and

Watt (1991) indicated that seniors who revealed integrity in their reminiscence were more likely to be healthier and happier than those who did not. Hence, death may not be so threatening to those who see the fundamental meaning of their lives unaffected by it.

Importantly, Wong and associates' (1994) study noted many middle-aged and older adults (47-90 years) avoided thoughts of death, which may prevent individuals from dealing with thoughts and feelings of death, resulting in psychological discomfort. Moreover, this study illustrated high positive correlations between neutral acceptance of death and well-being and depression. Relatedly, Neimeyer's (1994) aging studies revealed that fear of death and death avoidance were associated with psychological distress and depression. This is especially significant for those nearing death who are experiencing painful physical symptoms, such as the terminally ill. As Baines (1990) points out this can result in anxiety and insomnia, exacerbating physical pain, and reducing one's quality of life. Therefore, death acceptance is an adaptive attitude for those approaching death.

In sum, there is substantial evidence that death acceptance and death fear are related to the pursuit of personal meaning (Neimeyer, 1994). Explicitly, whether one fears or accepts death is influenced by an ability to locate personal meaning in life. Alternatively, research also indicates that death anxiety may be an obstacle to achieving meaning; acceptance of death may facilitate purpose in life or, explicit meaning and purpose may facilitate death acceptance (Amenta, 1984). Presumably, those who have not resolved fear of death will have an unclear meaning in life. Regardless, for those approaching death, meaning or purpose in life should not be considered independently from the awareness of death (Rappaport et al., 1993). Furthermore, death acceptance has been associated with well-being, a valuable component for one's quality of life.

Well-Being

This concept is a significant issue for the terminally-ill, as evincéd in palliative care literature. Given the aim is no longer cure but the chance of living to one's full potential in physical ease and activity, promotion of an individual's health is essential to facilitate effective personal use of one's remaining time (Saunders & Baines, 1983; Varrichio, 1990).

Moreover, well-being has been associated with meaning. As previously mentioned, Fisk (1980) found depression, anxiety, and somatisation accompanied loss of meaning. Importantly, she speculated that it was the deficit of meaning which lead to physical and mental health decline and not the reverse. This finding is recently buttressed by Frankl (1992) who posits depression is a consequence of existential vacuum. Furthermore, the association

between clinical phenomena such as anxiety, depression, and suicide, with lack of meaning in life has been empirically validated (Carlsen, 1988).

For example, Zika and Chamberlain (1987) reported meaning in life to be a strong and consistent predictor of psychological well-being. The meaning constructed around illness has been demonstrated to have an impact on psychosocial well-being. For example, Lashley (1993) believed terminal patients may experience despair and hopelessness as a result of meaning deficiency. Furthermore, such elements may even be responsible for the development or exacerbation of physical symptoms (Lichter, 1991). Therefore the loss of meaning is likely to result in despair and reluctance to undertake endeavours which might lighten the burden of illness and improve the quality of life remaining (Lichter, 1991; Lichter, Mooney & Boyd, 1993).

In addition, unfinished business is a notable cause of distress for the terminally ill (Frampton, 1989; Lichter, 1991). Zerwekh (1993) points out this may keep an individual from giving up, instead fighting against death until their personal affairs have been resolved. Moreover, Lewis (1989) suggested that the method in which patients utilised the time remaining may be more important for adjusting to terminal illness that duration with the disease duration. Hence, it appears vital that unfinished business is resolved to facilitate productive use of this time.

Given the quality of patient life and their manner of dying are equally influenced by psychological and emotional factors as by their physical condition (Barkwell, 1991; Lewis, 1989; Lipowski, 1985; Steeves, 1992), this has particular importance for the terminally ill. Accordingly, the presence of meaning and purpose in one's life may contribute positively by mitigating death anxiety, improving the quality of life remaining and most importantly, fostering a tranquil and peaceful death (Cohen & Mount, 1992; Lichter et al., 1993).

Chapter Two

Conceptualisations of Meaning

Personal meaning is a highly subjective concept. It is not external, objective or verifiable (Watson, 1986). This construct has a dynamic nature: when faced with an experience that cannot be rendered meaningful, the meaning in an individual's life is perceived as dissipated. One cannot lose a little meaning, it is an all-or-nothing experience. However, meaning can be re-discovered when an event has been perceived as purposeful.

There are multiple approaches for conceptualising meaning. Various theorists have examined the construct of meaning and developed specific theories in accordance with their research findings. These include: Thompson and Janigian's Life Scheme Framework; Frankl's Theory; Coward's Theory; and Reker and Wong's Theory.

Thompson and Janigian's (1988) Life Scheme Framework model is based on the work of Janoff-Bulman and Frieze (1983) and other personal theorists. This model provides a framework for understanding the search for meaning in terms of a cognitively socially-constructed representation of people's lives following the experience of an extreme stressor (Rothbaum et al., 1982; Taylor, 1995; Thompson & Pitts; Kleinman, 1988). According to this model people conceive their lives in terms of the events they have experienced, goals they have acquired, and others they wish to achieve. Events in life are interpreted from one's perspective of world and self views and assessed by their participation in goal acquisition. Within this framework, self and world views provide stable assumptions about life and offer individuals a list of expectations about future happenings (Janoff-Bulman, 1992). Procurement of desired goals are fundamental. Meaning is conceived as a method which organises unrelated events in a coherent understandable way and increases the likelihood of attaining desired goals. This facilitates order and purpose (Thompson & Janigian, 1988). However, in order for this system to operate, individuals must believe in the accuracy of their worlds while also being committed to some goal(s).

Unlike the previous theory, Frankl (1963) hypothesised that meaning is ultimate, and individuals are not conscious of it (O'Connor & Chamberlain, 1996). He maintains that a fundamental meaning and purpose already exists in the world, but must be personally discovered by individuals (Frankl, 1959). This is in contrast with Yalom (1980) who posits that meaning does not pre-exist but is created by the individual. Within this theory meaning is discovered by self-transcendence; through what individuals contribute to the world, what they

take from the world, and the methods adopted when faced with something out of one's control (Rappaport et al., 1993).

In addition, Frankl proposed that the drive to discover meaning is a primary concern and motivating force in human life. Because this need for meaning is innate, Frankl (1967) felt a search for meaning that is repressed or blocked will result in an individual developing an "existential vacuum" (a feeling that life has no meaning or purpose.) Given meaning changes in accord with events, but never ceases, it always exists although sometimes experiences make it difficult for individuals to locate personal meaning. Finally, Frankl (1962) asserts that if purpose in life exists so must purpose in suffering and dying. He argued that humans are free to choose their reactions to life: *"The last of human freedoms - to choose one's attitude in any given set of circumstances, to choose one's own way"* (Frankl, 1959, p.861). Therefore any individual can regardless of circumstance, decide what will become of himself/herself - mentally and spiritually (Frankl, 1964).

Doris Coward provides a framework for understanding the search for meaning based on Frankl's concept of self-transcendence. This model is established empirically on her investigations with advanced breast cancer and HIV sufferers. Her theory conceptualises meaning as an experience where one reaches out beyond personal concerns or inside oneself to find increased self-understanding, resulting in feeling connected with others (Coward, 1989; Coward & Lewis, 1993). Coward also incorporated Reed's nursing theory, which explored the concept of transcendence in the elderly as a resource related to mental health. According to Reed's (1991) theory, individuals find transcendence through a variety of avenues: inward expansion of personal boundaries, increased self-awareness and introspection; outwardly in relationships with others and the surrounding environment; and temporally, by integrating perceptions of one's past and future in a way that enhances the present life.

Reker and Wong's (1988) approach combined elements of Frankl's and Maddi's conceptualisations of personal meaning, with the cognitive approach of Kelly. According to Kelly's (1955) personal constructs theory the individual is able to interpret their experiences in a variety of ways. This process entails comparing and contrasting particular taxonomies and categories. The fundamental postulate is that every individual is motivated to seek and find personal meaning in existence, and this action is a conscious one. This framework describes meaning as a cognitive mediating variable which provides an interpretation of life experiences and integrates the variety of life events (Reker, 1985). Moreover, construction of meaning assists in the process of assimilating difficult experiences that occur throughout life. Personal meaning is defined as a multi-dimensional construct with at least three related

components: The first involves a cognitive component in which an individual makes sense of experiences in their life. A motivational element encompasses the process of pursuing selected goals and the eventual attainment, providing a sense of purpose and meaning to one's existence. The affective factor is the feelings of satisfaction and fulfilment that accompany the realisation of personal meaning. Within this framework individuals discover meaning from events that arise throughout life. They also create meaning through making choices, taking actions and entering into relationships. The search for meaning is also proposed to be conducted in a self-reflective manner. Consequently, personal meaning may be defined as the cognizance of order, coherence and purpose in one's existence, the pursuit and attainment of worthwhile goals and an accompanying sense of personal fulfilment (Reker & Wong, 1988).

In retrospect, meaning has been hypothesised in a variety of ways. Some theories highlight meaning as a ultimate construct, while others observe it from a phenomenological perspective. Similarities and differences also exist within these hypotheses. For example, Frankl's (1963) theory is congruent with the nursing conceptualisation of self-transcendence; transcendence is achieved by reaching out to others and in toward oneself. However, Frankl's conviction that meaning is attainable through one's attitude toward an unchangeable situation, is not asserted as strongly within Coward's theory. In addition, Frankl's approach is simpler than the Life Scheme Framework and is not limited to negative situations. However, given Frankl's description of meaning as an unconscious activity, it is difficult to understand and define the pursuit of unique personal meaning when one is unaware of executing this. Reker and Wong's (1988) theory and the Life Scheme Framework are both goal-oriented and unlike Frankl, posit the search for meaning is a conscious one. Albeit, Reker and Wong's and Frankl's theories propose individuals are motivated to pursue meaning.

Chapter Three

The Search For Meaning

The search for meaning occurs when part(s) of a person's life scheme is challenged by negative events whereby that scheme no longer provides a sense of meaning and purpose (Thompson & Pitts, 1993).

Why Do Negative Life Events Trigger A Search For Meaning?

Life seems meaningful for an individual when they perceive the world operates in an orderly fashion and they have important goals which provide a sense of purpose and are attainable (Thompson & Pitts, 1993). Presumably it is adaptive to believe that we are essentially good people who hold some control over our lives (Lefcourt, 1976; Thompson, 1981). However, various negative events can displace one's sense of order with confusion, disorder, disintegration and lack of control (Kleinman, 1988; Rothbaum et al., 1982; Taylor, 1995). Given meaning is an inherent basic desire, this motivates the individual to evaluate the possible causes, its impact and reactions in order to regain equilibrium and control over their life. Several reasons exist why traumatic events are likely to threaten one's representations of life and create a search for meaning:

1. Major life events are likely to question the accuracy of individual world views.

Work with victims suggest that people generally operate on the basis of important assumptions about themselves and the world which generally go unquestioned and unchallenged (Janoff-Bulman & Frieze, 1983). Major events question each of the primary postulates of one's assumptive world and by doing so, destroys the stability necessary for people to function in their daily lives (Janoff-Bulman, 1989; Janoff-Bulman & Frieze, 1983; Parkes, 1975). Therefore, when an individual's basic construction of the world is flawed by an event, revision is requisite (Epting & Neimeyer, 1984).

Interestingly, Antonovsky (1988) argued people possess a global orientation toward life which measure expressions of confidence that the world is predictable and they possess resources that can meet life's demands. Evidently, this exhibits similarities with the Life Scheme Framework and appears to support the assumption that negative events mandate a search for meaning. More recently, Antonovsky (1993) reviewed 26 studies of retirement samples and found many reported a positive relationship between this global orientation to oneself and their environment, self-esteem and well-being. This highlights the importance of the fit between one's confidence in the world and experiences encountered throughout life.

In addition, individuals may perceive the negative events as selective which may result in their questioning "why did this happen to me as opposed to someone else?" (Janoff-Bulman & Frieze, 1983; Taylor, 1983). Because of the basic human instinct for survival, for reasoning, and for emotional self-awareness, the questioning of why, when confronted with negative events is constantly raised (DeBellis, Marcus, Kutscher, Torres, Barrett, & Siegel, 1986). When people have successfully answered the "why me?" question, they have evolved a personally acceptable cognitive explanation for their predicament that helps them understand their experience - they have derived meaning despite their situation (Haberman, 1987).

Turnquist, Harvey and Anderson (1988) found that individuals with life-threatening illness search for an attempt to understand these unexpected and stressful events. Pennebaker (1990) observed that traumatic experience is particularly upsetting when one is unable to make sense of it. Consequently, this is likely to result in questioning the validity of self and world views and instigate a search for meaning. In contrast, Lauver, Barsevick and Rubin (1990) found the frequency of spontaneous causal searching for those with abnormal papanicolaou test (pap) results was not overwhelming. However, this discrepancy can be explained partly by the fact that causal searching was assessed immediately after learning about the pap results. Other researchers have found that engagement in causal searching increases with time after learning of an unexpected event (Gotay, 1985).

2. Negative events can challenge one's life scheme because these circumstances may make it difficult, if not impossible to achieve previously important goals.

A traumatic event such as a disease, an accident, a crime, may result in physical disability, financial problems, or the disruption of daily life, decreasing the likelihood of attaining future goals (Haberman, 1995, 1987; King, Grant, Ferrell & Sakurai, 1985; Thompson, 1991; Thompson & Janigian, 1988). Furthermore, such limitations in functional roles are particularly relevant to life's meaning because loss of such roles can diminish a person's sense of purpose and direction in the world (Cassell, 1982).

Oncological research has demonstrated the importance of goal attainment. For example, O'Connor and associates (1990) noted the majority of subjects discussed the consequences of cancer in relation to its effect on everyday activities and experiences which limited performance of typical life roles. Similarly, Fife (1994) found the threat serious illness posed to the attainment of future goals was also pointed out by individuals. Specifically, Heidrich and associates' (1994) study indicated that symptoms which intervened with one's abilities to carry out meaningful roles made it less likely for these ideals to be achieved. Further, Weisman and Worden (1976) found patients who perceived their illness

interfering with family, career or personal life were more likely to experience greater stress following diagnosis. Coward (1990) illustrated the disruption of goals that had previously given a sense of purpose in life, resulted in feelings of meaninglessness and lack of purpose. Finally, Davies (1997) HIV study revealed some described the "closure of possibilities" represented by the absolute certainty of death, which created an emptiness and seeming futility, rendering it impossible to find enjoyment in the present. Clearly, life-threatening illness and its treatment may mandate a need to re-evaluate views and activities which formerly gave life purpose and meaning but are no longer possible or appropriate (Haase, 1987). Apparently when a negative life event diminishes the probability of goal acquisition, to regain trust and control in one's life scheme and purpose in life, an individual will search for meaning in their experience.

3. Negative events can raise the issue of mortality.

A negative experience may challenge one's personal and world view if it raises the issue of mortality. Erikson (1963) posits that as death approaches individuals attempt to affirm that life has meaning and purpose, a point reiterated by Lichter and associates (1993). Fulton (1976) suggested that during these critical times people are more conscious of their mortal nature and engage in serious efforts to provide some solution to the obvious conflict between wanting to continue living and the knowledge that they must eventually die, which may involve a search for meaning.

Naturally the awareness of personal mortality will be heightened for the terminally-ill, perhaps resulting in a universal search for meaning. Substantial evidence illustrates that those living with life-threatening illness search for meaning (Baird & Dyk, 1956; Dirksen, 1995; Haberman, 1987; O'Connor et al., 1990; Steeves, 1992; Taylor, 1983; Turnquist et al., 1988).

The need to create new meaning has also been documented among cancer patients at various stages (Baird, 1956; O'Connor et al., 1990; Shanfield, 1980). For example, search for meaning has been identified in the newly diagnosed cancer patient as a prevalent thinking process (Germino, 1984; McCorkle & Benoliel, 1983). Weisman and Worden (1976) refer to this period as "existential plight", when existential concerns relating to meaning of life, illness and death predominate. This involves understanding the significance of the cancer diagnosis while also redefining meaning in life (O'Connor et al., 1990). Equally, evidence suggests the search for meaning may be particularly widespread or intensified among people with recurrent cancer (Chekryn, 1984; Mahon, Cella & Donovan, 1990; Scott, Goode & Arlin, 1983; Taylor, 1993; Weisman & Worden, 1986). Finally, studies have also recorded

this activity among late-stage cancer patients (Coward, 1990; Gotay, 1985; Mumma & McCorkle, 1983).

As previously mentioned, locating meaning in life experiences is universal and advantageous. Baumeister (1991) concluded that this drive to make sense of experience and find meaning in life can be elaborated into four needs for meaning. The first is purpose which involves interpreting present events in relation to future events. The second pertains to value and justification which encompasses finding a firm criteria of right or wrong that can be used to justify one's actions and to provide a sense of being a good and moral person. The third need refers to efficacy which incorporates the recognition of a method or simply achieving a sense of exerting control over one's life in order to achieve positive outcomes. The final need is that of self-worth, confirming one's superiority over others or affirming personal good qualities. Clearly, the experience of terminal illness or life-threatening illness highlights the awareness of one's mortality and instigates a search for meaning in life.

Chapter Four

Finding Meaning Following A Major Life Event

When an individual's system for maintaining order and purpose in life is interrupted by a significant negative experience, there are several methods in which one can find meaning again:

1. Change the life scheme:

As formerly mentioned, given meaning is comprised of both order and purpose, it is insufficient that the life scheme is only able to clarify one's experience; the standard for restoring meaning must also include world and self views that are consistent with setting and obtaining personal goals (Thompson & Janigian, 1988). Interestingly, this may result in the adoption of a negative view of the world, for example, no longer perceiving the world as safe. However, provided desired goals can still be attained, meaning will be renewed. Research has demonstrated that negative events often cause individuals to modify the meaning and structure of their lives by reordering priorities, adjusting their world or personal views and by encouraging the change of plans, and actioning important decisions. Taylor's (1983) study found half of her breast cancer subjects reported life reappraisal due to their experience with cancer; they verbalised new attitudes toward life, increased self-knowledge, and/or reordering of priorities, with a new emphasis on relationships. Carter (1993) found informants described going through a survival process with one phase involving focusing and reordering of priorities in life. They also made changes in lifestyles and life goals. Similarly, Moch's (1990) study found participants with breast cancer created new perspectives regarding goals these included: greater appreciation of others, more time spent on self, and greater enjoyment of life.

In addition, Thompson and Pitts (1993) identified two types of goals which may affect the likelihood of achieving a sense of meaning and purpose following a major life event. The first involves external, materialistic goals, such as accumulating wealth, and advancing one's career. These are likely to be difficult to maintain following a negative event such as a cancer diagnosis because of fatigue and time-consuming therapies. Furthermore, a terminal illness may compel one to question the value of these goals, whereby they no longer deliver a sense of purpose. The second encompass internal, non-materialistic goals, such as living one day at a time; these are still attainable despite the presentation of cancer. Therefore, the latter type of goal continues to offer a sense of purpose and direction.

Evidently, the modification of one's life scheme whereby goal acquisition is still feasible, is a tangible method to ensure meaning construction when faced with a negative life event.

2. Change one's perception of the event:

This may be possible by accentuating the positive aspects of an inherently negative event (Taylor, Wood & Lichtman, 1983; Thompson & Janigian, 1988). As already mentioned, the proclivity to find and focus on the positive side of negative experiences is noteworthy (Curbow, Legro, Baker, Wingard & Somerfield, 1993; Dieh, Haas, & Schaefer, 1994; Taylor et al., 1983). Further, a negative experience is less likely to challenge favourable beliefs about oneself or the world if one concentrates on positive aspects surrounding the experience; assumptions which generate a positive interpretation of the event or its consequences make it easier to find meaning because this is less of a challenge to one's sense of meaningfulness (Thompson & Pitts, 1993).

Several cancer studies have illustrated that individuals found meaning by changing their perception of their illness. For example, Haberman's (1995) bone marrow transplant (BMT) study noted that finding benefits, making social comparisons, and reappraising priorities were methods employed to discover meaning. Similarly, Taylor and associates' (1983) subjects developed a process of redefining their experience which included: comparing with less fortunate others, comparing on the basis of a favourable attribute, creating hypothetical worse worlds, and construing benefits from their experience.

Finally, perception of the event may be altered to conform with one's life representation if purpose can be elicited from the event. To illustrate, in several cancer studies where individuals reported purpose in their illness, for example, learning a lesson from their experience, and developing new goals, the illness was described as a positive experience (Taylor, 1983; Taylor et al., 1984; Thompson, 1985, 1991).

Summary

Investigation has established the construction of meaning in life in response to major negative life events performs a crucial role in the management of these experiences. Meaning has also been shown to direct the approach an individual adopts in response to serious illness. The association between sense of meaning and physical and psychosocial well-being, provide empirical evidence of its utility (Taylor, 1993). Practical research has also highlighted the importance meaning has upon the well-being of the elderly. Given the numerous changes and losses encountered in later life, this faction are particularly vulnerable to loss of meaning.

Clearly, the ameliorative qualities associated with locating meaning in life make this a pertinent concern for those presented with terminal illness. Research has also indicated a relationship between death anxiety and the inability to discover personal meaning when facing death. Thus, highlighting the salience of this issue for the terminally ill; death anxiety is an obstacle to accepting death and decreases the quality of life remaining.

The construct of meaning has been hypothesised by a number of theorists, with inherent similarities and differences: the Life Scheme Framework infers the search for meaning is pursued when events unbalance personal assumptions about the world and impede goal achievement. This theory presents meaning as a concept that is conceived consciously within a social context with a focus on goal acquisition. Oppositely, Frankl posits meaning is unconsciously sought and can be located in the most adverse situations. He also proposed meaning is present everywhere but must be personally discovered. Also unlike the former theory, this formulation is not goal-oriented; meaning is achieved through self-transcendence. Coward advanced that meaning is discovered through introspection, resulting in feeling closer to others. Reker and Wong's theory purports that finding personal meaning is an interpretive, conscious action where one seeks to represent extraordinary experience, which influences subsequent behaviour. Given this theory has adopted other assumptions, similarities with the previous theories are inevitable. For example, the subjective nature of meaning and the universal motivation to discover meaning, echo Frankl's theory. The importance of goal pursuit and attainment are elements shared by the Life Scheme Framework. Finally, Reker and Wong's theory posit that achievement of personal meaning results in positive contentment.

There are a variety of reasons to search for meaning: negative life events threaten the accuracy of one's world view, resulting in an unstable perception of the world. Life schemes are also jeopardised when previously significant goals become difficult or impossible to accomplish. Finally, a major life experience may be a reminder of individual mortality and initiate a search for meaning to relieve anxiety.

In the event of a negative life experience, meaning can be found through a variety of methods. For example, this can be realised by modifying an individual's world or self assumptions and goals, provided this remains in accord with goal acquisition. Redefining the experience appears to be an equally viable method to lessen the impact of negative events upon one's assumptive world and facilitate the construction of meaning (Janoff-Bulman & Frieze, 1983). This includes deriving positive meaning and purpose from the experience.

Finally, although it remains unclear as to the underlying mechanisms, research has clearly demonstrated that meaning is integrally associated with an individual's physical and psychosocial well-being (Taylor, 1993). Therefore, meaning in life should be explored as a potential medium of therapeutic exchange for the terminally-ill.

Chapter Six

Meaning As Therapy

> **"To help people to be able to tell their own stories and to work with and within these stories is the core therapeutic function."**
> *(Stein & Apprey, 1990, p. 227)*

Given that positive well-being is associated with meaning, this construct appears a promising medium for health promotion for those approaching death (Butler, 1988; Fisk, 1980; Reker, Peacock & Wong, 1987), particularly the terminally-ill. Indeed research suggests that a sense of meaning in late-stage disease is an important focus for therapeutic exchange (Lewis, 1989). A method to achieve this Cunningham (1993) argues, is to produce a life story which promotes meaning construction. Engaging in life story can clarify meaning in one's experience by affording closure or a sense of completion at the end of one's life (Lashley, 1993). It can also bring order to random happenings, making sense by reconstructing and reinterpreting experiences (Riessman, 1993).

This involves the process of reminiscence, a procedure which many researchers assert lacks a clear conceptual definition (McGowan, 1994). Accordingly, investigators have attempted to distinguish different types of reminiscence experiences by considering the context in which they are experienced. However, given the present study is specifically interested with the reminiscence process of those approaching death, McMahon and Rhudick's (1967) definition will be adopted. This defines reminiscence as *"the act or habit of thinking about or relating past experiences, especially those considered personally most significant."* This will include Butler's (1963) premise that this involves a universal process in which individuals reflect back on their life to deal psychologically with matters that are troubling or preoccupying them. Apparently this may embrace both positive and painful memories. Hence, reminiscence within this context refers to a life review process.

The life story is valued for assisting people to regain self-worth and meaning in life by reconnecting to earlier accomplishments, fond memories and valued identities (Kaminsky, 1984). Past events significantly influence the present and future (Fitzpatrick & Donovan, 1978; Neisser & Fivush, 1994). As Ricoeur (1985) enumerated *"More than just a happy escape into the past, the activities of reinterpreting one's past purportedly lead to an improved sense of personal identity and meaning."* (p. 75). Equally, this may involve solving current problems by identifying previous strengths and methods of coping employed successfully in the past (Havighurst & Glasser, 1992).

More importantly, the benefits of reminiscence as a therapeutic activity have been well documented. Research has associated this experience with psychological and physical well-being (Kaminsky, 1984; Myerhoff, 1978, 1982). For example, reminiscence has been positively linked with self-esteem in several studies (Haight, 1988; Havighurst & Glasser, 1992; Ingersoll & Silverman, 1978; Lappe, 1987; Lewis, 1971). Other empirical studies have related reminiscence to disposition; decreasing negative moods or increasing positive mood states (Brennan & Steinberg, 1984; Hyland & Ackerman, 1988; Oliveria, 1977). More recently, McGowan's (1994) reminiscence study reported elderly subjects derived status from their role as mentor with college students. This, combined with evaluative-reminiscence/life review produced improvements in self-esteem, depression, and subjective quality of life for the elderly participants. Moreover, these findings suggest evaluative-reminiscence/life review may be beneficial for individuals in need of resolving troublesome or regretful experiences, a pertinent issue for the terminally-ill.

Pennebaker's (1990) research examining the healing factors of psychotherapy, proposed coping with traumatic events can be expedited through writing about these experiences. To illustrate, one study investigating survivors of life-trauma found in comparison with the control group, those who wrote about their encounters showed significant improvements in immune responsiveness, physical health, and remission from other psychosomatic symptoms, such as headaches (Mishara, 1995). It is argued that language brings about the organisation and assimilation of traumatic memories and experiences, thus illustrating the benefits of translating traumatic memories into language. This point is reiterated by Murray (1994) who posits that stories are a means of overcoming crisis by restoring order and structure.

In addition, life review has been suggested as a means whereby a dying person can *"complete the last chapter of his or her own"* (Birren, 1987). By reviewing past relationships and events, the individual is given the opportunity to make things right or to tie up "unfinished business" (Clyde Nabe, 1989). Further, as Moloney's (1995) life review study reported, those involved in this activity generally involved expressions of having found peace within their lives. This finding highlights the cathartic nature of narrative.

Interestingly, Hughston and Merriam (1982) suggest that the duration of reminiscence is an important factor affecting the meaning derived from this experience. Presumably a life review, given it encompasses a whole life, may increase the likelihood of locating meaning.

Evidently, reminiscence is a therapeutic activity that may assist individuals in dealing with a variety of concerns, including unresolved conflicts, reconciling relationships, and previous losses. It is equally beneficial in facilitating the recognition and appreciation of one's inner resources. Combined, these factors can assist in locating meaning in the significant life events that shape the present (Butler, 1963; Huber & Miller, 1984; Kovach, 1991, 1990; Lashley, 1993).

Consequently, discovering meaning may enhance the quality of life remaining and assist in achieving a more tranquil death (Lichter et al., 1993). Hence, meaning in life is a highly salient issue for the terminally-ill, which can be constructed through the use of narrative.

Chapter Seven

Narrative

"persons give meaning to their lives and relationships by storying their experience."
(White & Epston, 1990, p. 13)

The narrative construct refers to any spoken or written presentation (Polkinghorne, 1988). Events and happenings are used to contextualise stories, and comparisons with other events establish a story (Coffey & Atkinson, 1996). These stories organise events temporally through a plot formation in which past, present, and future experiences are framed in a structured way (Baumeister & Newman, 1994; Coffey & Atkinson, 1996; Corradi, 1991; Cortazzi, 1993; Culler, 1981; Denzin, 1989; Kerby, 1991; Chamberlain, Stephens & Lyons, 1995; Sandelowski, 1991). Plot is the narrative structure through which individuals understand and describe the connection among the events and choices that occur in their lives (Bruner, 1990). Stories are sustained emplotted accounts with a beginning, middle, and end (Polkinghorne, 1995). Interestingly, Waitkin and Magana (1997) pointed out that narrative does not require completion as a coherent whole to generate a meaningful story. Central to the plot structure are situations encountered throughout one's life, with the methods selected to resolve these (Sarbin, 1986). The meaning of these events are dependent on their place in the plot's sequence (Bruner, 1990; Kerby, 1991).

Given a narrative can only be told from the finish, events are selected relevant to the endpoint; one is not free to include every occurrence but only those relevant to the story's conclusion (Brooks, 1984; Hermans & Hermans-Jansen, 1995; White & Epston, 1990). Therefore individuals have to select and arrange different events and situations in such a way that the endpoint is rendered more or less probable (Gergen & Gergen, 1984; Hermans & Hermans-Jansen, 1995). Hence, this construction is not arbitrary, illustrating the coherence of the narrative. However, in conjunction with the definition offered by Waitzkin and Magana (1997), narrative may include segments of discourse that present complete stories plus briefer fragments, sometimes interrupted or incompletely expressed.

Stories express a kind of knowledge that uniquely describes human experience in which actions and happenings contribute positively and negatively to attaining goals and fulfilling purposes (Mancuso, 1986; Polkinghorne, 1995). Similarly, Gergen and Gergen (1988) posited that narratives can be classified into different typologies according to goal direction within the plot: as the narrator moves from one event to another, they also approach or move away from the desired life goals, creating a sense a direction. This gave rise to three

general evaluative processes of narrative structure based on the story's movement: progressive, regressive, and stable narrative typologies. The progressive form refers to a positive personal construction of negative events and experiences in terms of personal goals constituted either prior to onset of illness or continuously following this event (Gergen & Gergen, 1984; Robinson, 1990). A range of sub-type narrative patterns also exist within progressive narratives, which relate to the introduction of illness. These concern the assertion of personal control over illness and management of the challenge imposed by the illness. The most enchanting are those defined heroic (explicit and implicitly). Explicit heroic narratives are established around a positive and definite progression towards valued life goals preceding diagnosis. .The impact of illness does not vanquish this advancement, but rather is heightened by special actions, behaviours and attitudes. For implicitly heroic narratives, the courage within the story is more strongly emphasised by the everyday success of life before the diagnosis (Robinson, 1990).

Another sub-type pattern which progresses toward valued life goals when faced with illness, are described as detective stories. These present illness as a mystery, enumerating definite efforts to unravel the personal mystery of this experience. This pattern is concerned mainly with asking "why me?" followed by "what can I do about this?" Given the frequent extensive period between symptom onset and formal diagnosis, drama and suspense develop as fundamental causes of symptoms are pursued and potential personal remedies to these are sought. The investigative search for answers establishes a positive narrative, regardless of whether solutions are found (Robinson, 1990).

Conversely, the regressive type presents a story of a continual and increasing discrepancy between desirable personal goals and the possibility of their attainment. Finally, the stable pattern illustrates a narrative that links incidents, images, or concepts in such a way that the individual remains essentially unchanged with respect to the valued life goals (Gergen & Gergen, 1988); life simply goes on, neither better nor worse (White & Epston, 1990). This pattern is the most 'unstory like' because lives are constructed as series of events or experiences lacking personal context. The progressive and the regressive types are most common because personal trajectory of illness is not highly correlated with physical course of disease (Robinson, 1990).

In addition, study of narrative demonstrate that stories are not simply told by individuals after their experiences; people live out the events of their lives in a storied fashion (Helfrich, Kielhofner & Mattingly, 1994; Lieblich & Josselson, 1994) As MacIntyre (1981) highlighted, *"Stories are lived before they are told"* (p. 197). Similarly, Ochberg (1988) argues that there is no way to disentangle living a life from telling or performing a story;

individuals conduct their life episodes in patterns similar to the plots of stories. We describe ourselves within a temporal framework, that is, we refer to our past, present, and future (Fitzpatrick & Donovan, 1978).

Accordingly, narrative theorists posit this medium is a pervasive form for organising ideas about reality and ourselves (Chamberlain et al., 1995). This is the fundamental scheme for linking individual human actions and events over the life span into a coherent formation (Gergen & Gergen, 1988, 1984; Polkinghorne, 1988; Richardson, 1991; White & Epston, 1990). As MacIntyre (1981) suggests, coherence in one's life is only possible through narrative; incidents, events and actions can only be connected together to form a whole through the narrative. Hence, personal narratives are ways of expressing experience, and as reality can only manifest itself in us as experience, narratives are central to human existence (Steffen, 1997).

Evidently, stories appear to be the natural way to recount experiences (Sarbin, 1986). Individuals do not have to be taught how to tell stories; it is part of their cognitive repertoire (Kemper, 1984). Mishler (1986b) noted that people frequently understand and recapitulate their experiences in storied form. An explanation for the tendency to interpret events in narrative is that people make stories in order to make sense of their experiences (Baumeister & Newman, 1994; Bruner, 1990; Gee, 1985; Helfrich et al. 1994; Kemper, 1984; Mishler, 1986a; Neisser, 1994). When we try to make sense of aspects of our life or to understand where we have been and are headed, we use stories (Helfrich et al., 1994; Kerby, 1991). As White and Epston (1990) assert in order to understand an action it is necessary to place it within a context of preceding and subsequent events. Moreover, people often come to terms with problematic experiences by putting their thoughts and feelings into words (Matthews, Lannin & Mitchell, 1994). This is especially true of difficult life transitions and trauma (Coffey & Atkinson, 1996). As Isak Dinesen proposed *"All sorrows can be borne if we can put them into a story"* (cited in Arendt, 1958, p. 175). Therefore constructing a narrative account may be a vital first step toward understanding a traumatic event (Baumeister & Newman, 1994).

Narrative is also an effective method to gain insight into our self-image (Kovach, 1991; Neisser, 1994). Given self-understanding requires examination of various past, present and potential life events in a unified structure, narrative is expedient. Subsequently, when we seek to make sense of aspects of our life or to apprehend where we have been and are headed, we use stories to do so (Helfrich et al., 1994; Kerby, 1991).

Events that have played a significant part in the individual's life may form part of the narrative (Neisser, 1994), as do seemingly mundane activities of daily living (Barclay, 1994). In relating the elements of these experiences to each other, the teller asserts their meanings (Riessman, 1993; Rosenwald & Ochberg, 1992). Narrative achieves this by organising past and present events and human actions into a complete story, thereby attributing significance to individual actions and events according to their effect on this story as a unified whole (Bruner, 1990; Polkinghorne, 1988; Riessman, 1993; Rosenwald & Ochberg, 1992).

This process involves the activity of relating events to one another: a specific event never has a meaning in itself but reveals its meaning only when viewed in the light of something else (Hermans & Hermans-Jansen, 1995). Earlier events gain their meaning and significance as a function of later outcomes (Bruner, 1990). For example, Becker's (1994) elderly study found subjects who engaged in narrative reconstruction assisted in connecting their impairments with experiences and identities from the past, present and potential future experiences. Similarly, Fitzpatrick and Donovan's (1978) elderly study illustrated the present was experienced and interpreted in relation to the meaningful past. Framing life in this way enables the interpretation of life and fate from various positions (Hyden, 1995; Mishara, 1995). As Denzin (1989) elucidates interpretation clarifies and untangles the meanings produced by experiences. Notwithstanding, individual explanation is a subjective activity, interpretation gives meaning to an experience. Similarly, Burkhardt's (1994) study on women's understanding of spirituality demonstrated that by telling stories various discoveries were uncovered including: descriptions of personal journeys, awareness of self, and experiences that had affected, shaped and given meaning to their lives. In the presentation of these stories, *"they enfleshed an otherwise abstract concept."* As previously mentioned, meaning of life events was not always clear in the midst of the experience, rather it was in looking back that the women discovered a pattern of unfolding in their lives through narrative.

Naturally there are inherent pre-requisites for establishing meaning. For example, the construction of meaning can only be facilitated when one's context is taken into account (Corradi, 1991; Hermans, 1995; Holstein, 1994; Kerby, 1991; Sarbin, 1986). *"People do not create their biographies in a vacuum"* (Blaxter, 1993, p. 139). Narrative clearly promotes this as a context-sensitive mode of thought that best captures the uniqueness of human experience which encompasses reasons, intentions, beliefs and goals. As Calnan (1987) observed, the meaning derived from narrative is *"in itself derived from their own complex body of knowledge and beliefs, which is closely linked with social context in which they lead their daily lives"* (p. 8). Furthermore, given life accounts are often complicated, narrative is invaluable as this method is flexible and can accommodate inconsistencies more efficaciously

than paradigmatic approaches: *"Narrative, unlike logic, is not stopped dead by contradiction. Indeed, it thrives on it" (Bruner,* 1990, p. 350). Therefore this method is well-suited for re-interpreting and accommodating variable information, as well as assisting individuals reflect on situations which involve conflicts and inconsistencies (Baumeister & Newman, 1994).

In sum, individuals employ the story form to recite their experiences, which facilitates the construction of meaning. With regard to illness, personal narratives especially if told and retold in the presence of interested others can help those with serious illness to formulate new meanings (Holstein, 1994). Accordingly, examination of illness narratives will reveal an insight into the characteristics, events, and happenings central to the individual's organisation of this experience, namely personal meaning.

Chapter Eight

Use of Narrative In the Study of Illness

> **"It is because we all live out narratives in our lives and because we understand our own lives in terms of the narratives, that the form of narrative is appropriate for understanding the actions of others."**
> *(MacIntyre, 1981, p. 197)*

With the decline of medical dominance as the prevalent way of conceptualising illness and the increased concern towards chronic illness, new ways of understanding the patient's perspective of their illness has been emerging (Conrad, 1990). A promising tool which has been explored in this area is narrative. As one of the most powerful forms for expressing suffering and related experiences is the narrative, this technique is clearly efficacious (Hyden, 1997). Further as Frank (1995) asserted narratives not only articulate suffering but give the individual a voice for expressing this experience apart from how illnesses are conceived and represented by biomedicine. As Hyden (1997) and Kleinman (1986) posit, reducing illness to purely medical focus is detrimental to the understanding of illness as a human experience: they redefine the problem to remove that which is most innately human - beliefs and feelings.

Narrative is a crucial imaginative response for those who face the sudden threat of an illness, particularly a life-threatening one (Del Vecchio Good, Munakata, Kobayashi, Mattingly & Good, 1994). When faced with illness an individual is compelled to uncover the meaning of the disorder and its consequences within the context of their life. This occurs through the reconstruction of one's personal life narrative in which the illness is assigned a place within this story. By weaving the threads of illness experience into the fabric of our personal lives, physical symptoms are transformed into aspects of our lives, and diagnoses and prognoses attain meaning within the framework of our personal life (Hyden, 1997). Further, this also facilitates the creation of order and interpretation of events connected with the illness and the individual's life before its onset. Albeit, life-threatening illness is, to some degree, already invested with collective meanings inherited from one's cultural tradition, as an agent of meaning, the individual has the capacity to interpret these events in his/her own way (Hermans & Hermans-Jansen, 1995). These interpretations of illness will embody their attempts to deal with the problems of meaning linked with illness, pain, suffering and death (McGuire & Kantor, 1987).

In addition, the meaning derived from these stories will influence the individual's response toward this experience (Hyden, 1995). For example, certain stories mobilise tellers

to new actions thereby replacing the existing meaning structures (Rosenwald & Ochberg, 1992). Apparently stories motivate people because their ongoing action is experienced as the continuation of the story they are currently involved in - their life. This act of verbalisation implies an attempt not only to conceptualise the illness, but also to define it so the real work of understanding can begin (Mathews, Lanin & Mitchell, 1994). Hence, the *"storying of experience"* (White, 1990) creates a framework for individuals to understand and adjust to illness.

Evidently, illness narratives are a significant means for studying the social construction of illness as a *"rhetorically-bounded phenomenon"* (Frank, 1993). Narrative approach provides an opportunity for important information to be obtained regarding the individual's interpretation of illness, sources of personal meaning, and how they attach meaning to this experience. Particularly the forms these stories adopt can provide a window into the structuring of these experiences and the manner in which information is presented to produce the desired impact (Coffey & Atkinson, 1996).

Personal narratives of Multiple Sclerosis (MS) sufferers demonstrated the close association between illness and life. The consideration of Gergen and Gergen's (1984) narrative structure emphasised positive outlooks of many individuals with attempts to achieve personal control over the effects of the disease, more frequently than previous analysis indicated (Robinson, 1990). Further, these stories created and reinforced attempts at understanding and achieving personal control over the effects of the disorder.

Breast cancer narratives offered an understanding of the processes involved in adapting to this illness, these included: accommodating personal experience to pre-existing cultural models, modifying in light of new information, and confronting conflicts within one's interpretation of the meaning of illness (Mathews et al., 1994). These narratives incorporate and build upon cultural ideas about the causes of illness and about the illness itself as a way of transforming the illness into a part of one's own life, making the illness part of the shared culture (Hyden, 1997).

Similarly, Temporomandibular Joint (TMJ) narratives illustrated the reconstructions of personal experience reflected more widely shared cultural models. As Denzin (1986) suggested, *"Every life story is unique, yet representative of every other life story"* (p. 329). Specifically, cultural schemas of illness, mind, and body are used to interpret and represent experience and provide guidelines for present and future actions (Garro, 1994). In addition, some sufferers interpreted this illness as a necessary and valuable learning experience that

made their lives more rewarding. For example, a number mentioned an increased empathy towards the suffering of others.

Murphy and Kinmonth (1995) examined non-insulin dependent diabetics' understanding of this illness and their response to it. The use of narrative proffered an important insight into patients' reasons for nonadherence to medical advice: given their perceptions of diabetes and the personal implications, various explanations for not following medical advice regarding lifestyle were rational. Lang's (1989) use of narrative with diabetics and other community members was advantageous. This revealed general statements about this illness and its causes, combined with more personalised anecdotal statements concerning the course of an individual's particular condition. As Hyden (1995) highlights, illness narratives transform diagnosis and prognosis into recognisable phenomena. Similarly, analysis of Epilepsy narratives demonstrated multiple perspectives regarding this condition, suggesting alternative plots surrounding the cause and outcome of this illness. Further, these narratives also identified methods which allow sufferers and their families to justify continued care-seeking while maintaining hope for positive outcomes. Interestingly, they also acknowledged the potential for healing through stories about encounters with the mysterious (Good & Del Vecchio-Good, 1994), impressing the inextricable influence of one's belief system.

Narrative provides a window into patient perceptions of long-term and/or serious illness within the context of their lives. This is certainly an effective medium that promotes the conceptualisation of illness in order to understand and ultimately find meaning in this experience. As Early (1982) pointed out, illness narratives help people make sense of what is occurring by providing *"an arena for the negotiation of reality"* (p. 149), which enables individuals to *"find meaning or sense of coherence in the midst of the disruption which the illness has caused"* (Williams & Wood, 1986, p. 147).

To recapitulate, extensive research has clearly demonstrated that the construction of meaning is a central aspect of adaptation to serious illness. Furthermore, investigations reveal meaning is a concept that people seem willing to discuss freely and it appears to permeate all dimensions of their thinking relative to their illness (Fife, 1994). Specifically, investigation into these illness narratives illustrated that people attempt to make sense of their ordeals in order to give meaning to their experience (Luborsky, 1993). Clearly, the narrative medium facilitates expression of personal meaning. Hence, meaning attributed to illness will be embedded within the stories people tell and create (O'Connor & Wicker, 1995).

OBJECTIVE

Because meaning has been shown to have therapeutic qualities for the terminally-ill, an understanding of how this population constructs meaning is warranted. Given narrative is a natural medium that promotes meaning, this mechanism proffers an opportunity to examine how these individuals attach meaning to this experience. Consequently, the purpose of this study is to examine hospice patient biographies to determine how the process of constructing a biographical account contributes to meaning formation.

METHOD

The Hospice Programme of Care

The Te Omanga Hospice has been providing palliative care to terminal patients and their families in the Hutt Valley region since 1979. This organisation provides a free service funded principally by donations and grants from within the community. The Hospice Programme of Care is designed to meet the needs of these individuals both in their homes and within the hospice. The chief focus is promoting effective use of remaining time and facilitating a peaceful death. Despite the hospice's ability to relieve physical and psychological distress for patients, a feeling that life is meaningless is difficult to mitigate. Given the ramifications this has for patients' well-being, the hospice established a biography programme to help those they considered would benefit from reviewing their life. Dr Ivan Lichter, former medical director of the hospice extended life review to the more formal compilation of patient biographies. The biographers were carefully selected volunteer members of the family support team. They underwent a comprehensive training programme facilitated by an experienced oral historian, broadcaster, and a journalist who specialised in biographical projects. They attended regular group meetings with the coordinator and any concerns were discussed immediately. Issues of confidentiality were addressed during their training and emphasised regularly.

In accordance with the patients' requests, some completed biographies also included photographs, poetry, and art work. The tapes and written biographies were the property of the patient, to dispose of as they wished, and remained confidential. Typically, most patients present a copy to significant others.

Subjective assessment by patients, relatives and staff concluded this activity was beneficial in restoring focus, interest and meaning (Lichter et al., 1993). Today this opportunity is offered to every patient who enters the Hospice Programme of Care. However as *"there exists no objective evidence of their value"* (Lichter et al., 1993, p. 137), examination of these biographies would prove invaluable in discovering how meaning is found in narrative.

Procedure

We approached the hospice to explore the possibility of accessing these biographies for the purpose of a qualitative study (the hospice has an original collection of eight biographies held in their register). The hospice was supportive of this proposal which was carried out in collaboration with the education research officer. However, given these authors were deceased specific consent for their use in this project could not be obtained, raising the ethical issue of consent and ownership. Ethical consent for use of these biographies by the Massey Human Ethics Committee was approved pending the Hospice Trust Board's consent. With regard to the issue of consent it was decided that all patients who had prepared a biography gave express permission for their material to be used in projects associated with furthering the Biography Programme. This consent was obtained verbally from the patients as no formal written consent procedure was in place at that time.

The second issue of ownership also presented legal problems - who owns the biographies? The Trust Board decided use of these biographies should be consented by patients' families. However, several relatives, unaware these biographies existed, withheld permission. Therefore the number of biographies from the original collection was reduced to three. Following our request to study these biographies, the biography programme reviewed and developed formal consent procedures to overcome similar future difficulties. Subsequently, three recent biographies whose authors had given formal consent were also included in this study, bringing the total number of biographies to seven (one patient authored two biographies).

The Biographies

Following is a brief description of the biographies and authors. Given the stories were the principal focus of this study, the details provide an insight into the stories' contents rather than the authors themselves. Pseudonyms were used to ensure patient identity was protected. Quotations from these biographies were also abridged in order to safeguard this.

Mark

Mark suffered from cancer of the kidneys which metastasised to his lungs. He was divorced with three children. Career and sporting achievements featured predominantly throughout his life account. He had produced two different biographies, both delivered in the first-person. The first biography was a circumscribed account about his illness. This included

important events leading up to the diagnosis of terminal cancer, and an insight into currently living with this illness. The second biography was a more comprehensive life story incorporating information from the first with a particular focus upon his career. Mark died following this aged 60.

Chapters were incorporated in the first biography. These related to specific episodes of the cancer experience. The employment of chapters (14 in total) provided a chronological account from *"the outset of my problem"* to the climax, *"the diagnosis of cancer."* Each title conveyed a premonition of a foreboding event, commencing with Chapter 1, *The First Warning*, culminating in Chapter 9, *The Death Sentence.* In addition, various titles were tinged with personal loss, indifference and subjugation. Some were a sober candid reflection of the situation - Chapter 10, *I'm Dying*, while others presented an almost carefree attitude - Chapter 4, *Welcome To Hutt Hospital.* In contrast, Chapter 14, *Life Goes On,* conveyed a poignant reflection of his life following the diagnosis which examined the present together with a focus into the future. The plot's climax, *I'm Dying* was followed by the light-hearted interlude, *My Friend John*, possibly a deliberate attempt to alter the lugubrious tone of the previous chapter. The final chapter, *Life Goes On,* closed this biography in a positive regard: although the biography was physically ended, it continued to look into the future.

The first biography was prepared some months prior to the second. Considering the time restraints imposed by his condition, storying his illness in the first biography, suggests he attributed significance to this experience. Unlike the first, the second biography represented a comprehensive construction of his past. Perhaps with completion of the first biography, time was less pressing, permitting a capacious life story:

> **Basically it [second biography] represents the whole of my life in a very condensed form** *(Mark).*

Notwithstanding, the reduced exigency in construction of the second account did not produce a great amount of personal insight, with areas examined superficially. Hence the decision to focus predominantly on the first biography.

Like others, Mark selected certain aspects of his life to concentrate on and ignored others: *"What you do with these things is you leave all the bad bits out so it doesn't actually leave very much."* This suggested he perceived his life was replete with negative experiences and chose not to share these with the audience. However, reference to serious negative experiences throughout his narrative suggest he chose to explore events which held personal significance, positive and/or negative, rather than benign episodes. This is reiterated by

Lieblich and Josselson (1994) who posit individuals select from an array those moments deemed important and omit those they prefer not known or were insignificant.

Richard

Richard experienced metastatic lung cancer. He was an orphan who emigrated from London as a young man, never married and had no children. Following the production of his biography he died aged 70. The pervasive issues of work and travel permeated this biography.

This biography was organised as an earnest, almost clinical account of a circumscribed life presented in the first-person. However, there was evidence of self-reflection - *"looking back"* was a device used to re-examine fragments of his past. A notable feature of this biography was the clarity of historical accounts, encompassing over 50 years. The richness of these details reflected what Heidegger (1962) called *"the nearness of the far."* Richard recalled distant memories as if experiencing them in the present. This quality was reiterated by the biographer as a prominent feature throughout its construction. Another striking characteristic was the chronological presentation: experiences were recounted in this precise manner, rather than one event triggering recollection of similar experiences. Accordingly, the biography opened with Richard's family history. However, given he was an orphan, there was little detail. Employment ensued, which dominated this biography. Being a military officer, various expeditions and adventures during the Second World War were examined. Following the war the focus moved onto civilian employment. Leisure activities and travel during this time were also recounted.

His illness account coincided with the end of his working career. Interestingly, the illness extract mirrored the prevailing character of this biography: concise and frank without dwelling on the limitations imposed by its onset. Further, unlike other biographies, Richard did not explore the nature of his illness; no description of and/or personal significance of the illness was offered, instead he considered the practical implications. Again this was consistent with the style of his biography.

In addition, several paramount issues within his life were re-explored; Richard discussed areas he wished had been concentrated on during his life. Significantly this was one of the few occasions during the entire biography where he reflected on important experiences during his lifetime. This extract was poignantly personal and blunt yet seemed deliberately choreographed to offer advice to the reader; the biographer recalled how delighted Richard was that others would be privy to its contents.

Simon

Simon had metastatic bowel cancer and melanoma. He was married with six children from three marriages. This biography was compiled and he died in December of that year aged 69. Autobiographical material written prior to the biography, together with samples of his poetry were incorporated into this biography. The biography focused chiefly on addiction problems, marriage dissolutions, his children, and spiritual faith.

This biography was a chronicled account with various sections comprising subplots of his life. Parts one-three contained autobiographical material written prior to the biography. Part four, the largest section, introduced the biography with a continuation of his life story. Two autobiographical stories were also included in this section. Expedient samples of his poetry were incorporated into the four sections. Presentation was in the first and third-person. In addition, throughout this biography Simon offered tributes to significant others. Although these were available to the reader, they remained private acknowledgments to those individuals.

Part one examined selected childhood memories including his entry into the airforce, a precursor to an difficult period in his life. Part two was described as *"my alcoholic life; alcoholic strife might be a better description."* This passage was a sombre, bleak account of life which revolved around addiction problems: entry into Alcoholics Anonymous (AA), marriage dissolutions, custody battles, psychiatric committal. Interestingly, the writing style within this section mirrored the turmoil - erratic and desperate. In contrast, part three offered an embodiment of hope. This section examined the period following his addiction and was testimony to restored faith. The pervasive theme was one of rebirth and inspiration.

Part four encompassed the biography. This section focused on significant events throughout his life, these included: his third marriage, birth of his youngest son, visit to in-laws overseas, the catholic church, alcoholism and affiliation with AA, the cancer experience. The two autobiographical stories included in this section recounted personal episodes. ***Our Secret Child*** described the apprehension surrounding the conception of his youngest child, and ***Parents Centre*** documented his experience of changes in expectant parenting techniques over the years. The biography closed with his poem ***Acceptance*** which epitomised how he prevailed despite demanding obstacles.

A distinction was apparent between the autobiographical material and the biography: the former was more unstructured, without censorship capturing the emotive qualities of these experiences:

An autobiography should be light, pleasant to read. How can I do this? I can say flippant things too easily; I'm afraid there's too much tragedy
(Simon).

Conversely, the biography presented a more uniformed, organised history. Construction seemed mindful that others would read its content and was organised accordingly: it was structured, chronological, and lucid. This was supported by the biographer: during the compilation Simon requested an unflattering comment regarding a significant individual be omitted because this person would be privy to this biography. Albeit, editing was influenced by the biographer, this demonstrated his sensitivity to potentially hurtful remarks. In addition, Simon assumed a more distant and objective role within the biography, unlike the autobiographical material where he appeared completely absorbed in the recollection. Given Simon had explored much of the biography's content within his autobiography freely, perhaps he felt compelled to present a more coherent story to the biographer and audience. This also highlighted the impact an audience may have on the narrator's story.

Clearly, this narrative was distinctive from the remainder: it was more reflective, combining interpretation with spiritual awareness. Furthermore, he seemed to analyse experiences profoundly, capturing this in poetry. Nevertheless, this is not intended as a criticism of the others, simply an observation.

David

David suffered from mesothelioma (lung cancer) caused by asbestos exposure. He was an emigrant, was divorced and remarried with two children. This biography was compiled and he died the following year aged 59. The construction was in the first-person. Like many, this biography was circumscribed, embodying a reflection of his life with an emphasis on his professional career and spirituality.

The biography opened with ***The Past,*** a brief synopsis about his family and educational history. A second segmented titled ***Anecdotes from Childhood*** was an exclusive recollection of growing up during the Second World War. Descriptions followed regarding his emigration to New Zealand. This encompassed early working experience as an emigrant, his marriages, a religious movement he was affiliated with, and family life. The final sections, ***The Present*** and ***The Future*** explored his illness. This was a simple yet powerful chronicle of his personal experience with cancer; how he coped and adjusted to its impact, with a focus on plans relative to the uncertainty of his prognosis. Spirituality was very prevalent in this section. The biography closed with a simple message proffered to inspire and teach the audience.

Margaret

Margaret experienced metastatic lung cancer. She was single with no children. Her biography was cut short by her death three months after her diagnosis aged 81. This biography was presented in the first-person with a primary focus on spiritual faith and family.

The biography opened with an exploration of her parents' background. The focus then moved to her immediate family and experiences growing up within a large close-knit environment. Following this Margaret examined an episode early in her adult life when she was seriously ill. Interestingly, this, combined with her current illness seemed to inspire reflection on spiritual faith, the cornerstone of her life. Within this section she described the various parishes attended and the close bond formed with the Catholic Church. In addition, Margaret reflected on the close relationship with her sister, and the many activities carried out together. Her daily routines as a working adult were also investigated, including dressmaking, singing in choirs, and concert parties during the Second World War. The final passage concerned her involvement with the Charismatic Movement. This briefly explored the healing masses Margaret participated in as a recipient. Unfortunately the biography is cut short here by her sudden death. Consequently, there was a paucity of detail regarding her illness experience.

This biography illustrated the inextricable character of recollection: although beginning as an historical account, certain issues or events triggered discussion of related areas, mirroring the nature of recollection. This employment of subplots seemed to enhance fluidity within this biography. Given there were no restraints upon areas examined, her focus upon family and faith emphasised the importance she attached to these.

Elizabeth

Elizabeth suffered from breast cancer with secondary leukemia. She was divorced with one child. This biography was written shortly before her death aged 63. Several autobiographical accounts produced before this biography were included in the appendix. The biography was a chronological account presented in the first-person with a pervasive focus on travel experiences.

Elizabeth's character permeated the biography and was captured in the tone of this account; although faced with imminent death she remained philosophical and recalled events with fondness. Her blunt manner was also evident. In addition, the title ***Clinging To The Wreckage*** was indicative of her strong spirit demonstrated throughout the biography.

Considering the close encounters with death experienced at birth and during her lifetime, this also illustrated her tenacity for survival.

The biography began with an exploration of her childhood during World War 2. This was followed by a brief exploration of events surrounding her education: the isolation she felt from being intellectually ahead of her classmates. She also examined her working career as a female journalist, a colourful time in her life. This was accompanied by recollections of her experience as a nurse working in rural regions. The issue of travel followed and dominated Elizabeth's biography; clearly a significant area in her life. Toward the end of the biography, experiences associated with her time at university featured extensively, highlighting its importance for her.

In keeping with the chronological nature of this biography, her illness was examined at the end. Interestingly, she included the autobiographical account ***On Being Diagnosed With Cancer***, in the appendix. This anecdote described the personal experience of cancer: diagnosis and living with the illness. A notable similarity with other biographies was the advice-giving nature of this passage; although this was not openly declared, it appeared written to provide information for sufferers regarding potential coping mechanisms drawn from private experiences. This account also emphasised misconceptions surrounding cancer and palliative care. Remarkably this direct passage engendered courage and inspired proaction to fellow sufferers.

Another autobiographical story ***Emergency At Ormondville*** described being a passenger on the Bay Express during a severe earthquake. This frightening event remained etched in her recollection. The final untitled account presented a synopsis of notable incidents throughout the biography. This focused on growing up in her hometown, which incorporated pleasant and moving recollections, accompanied by topical controversial issues. Scrutiny of more recent changes were also included. Although this biography was not a public document, Elizabeth utilised this opportunity to articulate condemnation of several contemporary practices:

> **I should also mention that sanity still prevailed in the Department of Education in those days. .. Successive city councils have done much to ruin the character of [city] since I left in 1957. But the council which permitted .. an ill assortment of small factories, many of which appear derelict, today - deserves utter ignominy**
> *(Elizabeth).*

The biography closed with the inscription chosen for her epitaph. The sentiment of this passage evoked the idea of an individual returning home, which having spent most of her life away from home, exemplified her life.

The predominant area of personal insight was located at the end. Evidently, having recounted experiences from the present lended itself to personal disclosure at the finale. This appeared a natural progression, also evinced in other biographies. A striking feature was the reference to historical incidents in which many expeditions coincided with famous events. In addition, a feature also found in other biographies was the clarity of recalled events. It appeared these memories held special significance for the authors. As Barclay (1994) stated affect gives certain recollections personal significance. A final interesting observation was Elizabeth's deliberate omission of personal issues in her life:

> **Biographies are significant for the details they leave out. Mine is no less significant than these because I have left out details which are very personal and which are really of no interest to other people**
> *(Elizabeth).*

This reflected her private nature. Although it would have been invaluable to have incorporated additional personal experiences, those mentioned were interesting and insightful. Therefore the construction of this biography was principally a collection of explicit memorable experiences rather than personal soul-searching per se.

Chapter Twelve

Analysis Procedure

This study employed narrative inquiry, a subset of qualitative research designs to examine the nature of meaning construction within narrative. Two methods of analysis were selected: analysis of narrative and storying meaning. Both approaches are interested in how human experience is represented within narrative and how this medium provides knowledge about this experience. Analysis of narrative was based on Polkinghorne's (1995) methods of narrative configuration. It classifies a particular instance as belonging to a category or concept (Baumeister & Newman, 1994). Each category or concept is distinguished from others by possession of exclusive attributes. This type of thinking attends to what makes the item a member of this category; it does not focus on what makes it different from other characteristics of the category. This produces cognitive networks of concepts that enable individuals to construct experiences as familiar by highlighting the common elements that appear frequently. The power of this type of cognition is the ability to bring order to experience by seeing individual things as belonging to a category. Specifically, the capacity to develop knowledge about established concepts from a collection of stories (Polkinghorne, 1995).

The second part of this analysis involved storying meaning. This approach offers explanatory knowledge concerning the reasons for individual's behaviours, allowing understanding of action. This was deemed important as the significance and contribution of particular happenings and actions are not explicit without placement in a coherent story (Polkinghorne, 1995). The collection of these storied experiences furnish a foundation for discerning new action episodes by comparison with previous action. With this approach the focus is on establishing similarity with a certain remembered episode. In this way comparison highlights the variability within human behaviour (Polkinghorne, 1995).

With analysis of narrative, stories are collected as data. The stories gathered in this study were a collection of seven hospice biographies. These were read to become familiar with the contents and recorded onto computer to enable expedient analysis. This information was studied for evidence of selected concepts which exist across the stories (Ruth & Oberg, 1992). Pre-selected concepts included Gergen and Gergen's (1984) narrative typologies, an evaluative process described as a useful method to analyse personal accounts involving illness (Robinson, 1990). This pattern differentiates accounts according to movement toward personally important goals. There are several reasons for this investigation. Firstly, goals

assume importance in stories and illness has been found to be a significant impact on this activity. Secondly, given purpose is derived from achievement of our desires and the acquisition of what we value, meaning will be realised through movement toward personal goals. Hence, this movement within biographies will be associated with meaning formation. Each biography was analysed for type of narrative pattern: progressive, including sub-types (explicit and implicitly heroic; detective); regressive; and stable. This involved examining the plot structure with regard to personally valued goals (occupational careers, personal relationships, personal ambitions), and the direction adopted towards (or away from) these. Inspection focused on similarities with this movement prior to and following formal diagnosis, in order to establish the influence this experience had upon goal direction across the biographies.

Investigation of narrative devices was also undertaken. Narrative features which contribute to meaning formation were concentrated on including: role; epiphany; closure; and metaphor. These features were examined for patterns, themes, and regularities present across the biographies. Although there are many other narrative devices, examination will concentrate exclusively on these fundamental features of narrative. Regarding roles, given these narrators are central actors in these stories, it was considered interesting to examine roles they assume in a story constructed facing death; specifically, how roles are affected by the interruption of illness. Moreover, considering meaning is related to goal direction, investigating the roles they maintain with regard to goal realisation is significant. Epiphanies are turning points which are important because they compel change and action. Given these accounts story lives disrupted by terminal illness, it is important to examine this turning point with respect to changes it coerces within the story with regard to meaning construction. Closure was another feature which warranted examination. Most stories have an ending which attempt to finish at a point of resolution. Considering these accounts are storied from facing death, it is important to examine the ending to determine whether this is established and how this was accomplished through narrative. With regard to meaning construction, in order to make sense of experience it is necessary to resolve unfinished business; closure involves resolution of unfinished business. Moreover unresolved conflicts can obstruct realisation of personal meaning (Erikson, 1961) and death acceptance. Finally, the narrative device of metaphor was also examined. This device is important because it demonstrates the manner in which individuals organise and express their experience (Coffey & Atkinson, 1996). Considering narrators make sense of their lives by reconstructing their life stories (Riessman, 1993), metaphor maintains an important role in this process: metaphor enables individuals to represent experiences through analogy in which new meanings may be offered.

In addition, given the detrimental impact death anxiety has upon meaning construction, inquiry will also focus on this concept and its association with the selected narrative features. Evidence of death anxiety within these accounts involved searching the data for the following properties: fear and anxiety about death; difficulties with death acceptance; and negative preoccupation with imminent death.

Storying meaning facilitates the methodical study of personal experience and meaning (Riessman, 1993), producing knowledge about particular situations. Given the complex nature of meaning and the richness of narrative, this approach enables the diversity of behaviour to be examined, capturing the intricacy of human experience. This approach functions to answer how a particular outcome came about: how meaning is constructed through storying a life facing death. Stories are gathered as data and examined for the processes of meaning-making in narrative. This involves a search for various sources of information that offer such explanations (Polkinghorne, 1995).

With this approach the biographies and biographer interviews were collected as data. Information from these interviews were studied to determine the nature of the environment the accounts were constructed within and the impact this structure imposed upon their construction. Given meaning is located in the context where the interpretation is made, this environment needs to be considered. As Murray (1997) noted, in considering any illness story you cannot abstract story from context within which it is told.

The nature of the study's was multi-layered adopting an interpretive position. Considering human experience is a complex issue, in order to understand this it is necessary to assess many concepts. Examination initially focused on identifying common and diverse themes within these accounts. Given the study's principal interest in meaning construction within narrative, a second level of analysis examined how narrative functions to produce meaning.

Inquiry revealed various sources of personal meaning, while death anxiety assumed a peripheral concern. With regard to meaning construction we also searched for processes of meaning-making within these stories.

Before the findings are disclosed it seems prudent to be mindful of the imposed structure on biography construction. Baumeister and Newmans (1994) highlighted the importance of the interpersonal context in which stories are told. They noted how motives influence the telling of stories. These included: the need to interpret events; to construct stories that depict their actions as right and good; to perceive you are able to make a

difference; to compose stories which promote self-worth; to obtain rewards; to have others confirm their identity; to transfer information; to captivate others (Murray, 1997). These motives illustrate the nature of the story will be influenced by the character of the context. Given the inextricable nature of this dynamic, this study elected to acknowledge its presence rather than concentrate extensively on its impact. Naturally the production of biographies will always be influenced to a degree, by the context they are constructed within, hence, this is not intended as a criticism, simply a factor to be cognisant of.

A narrator's story changes depending on the anticipated audience (Mishara, 1995). Considering these accounts were produced under the premise that others (family, friends, hospice staff) would be privy to its contents, this influenced the material included, reflected in the authors' remarks:

> **What you do with these things is you leave all the bad bits out**
> *(Mark).*

> **I always think that biographies are significant for the details they leave out. Mine is no less significant than these because I have left out details which are very personal and which are really of no interest to other people**
> *(Elizabeth).*

This element was reiterated by one of the biographers, who commented that during the initial draft an unflattering comment regarding a significant other was removed because they would receive a copy. Perhaps they do not wish to leave behind something of themselves which is negative; preferring to leave a positive living memory which will remain in other's memory, reflected in the following extract:

My grandchildren will have a spoken record of their grandfather now. Taping is a personal thing because they can hear you laughing. They won't hear me crying but they will hear me laughing and joking
(Mark).

Further, this editing highlights the coauthored nature of these accounts, influenced by the biographers. Other illustrations of this influence include the type of questions employed, coaching, and probing for information during the process of construction. For example, one biographer described her role as a *"sympathetic stranger"* because the narrator required *"little prompting and coaching: he had a mental list already to go."* It is difficult to determine the extent of the biographers' role in construction. For example, our interviews were carried out at various intervals following the construction, affecting accuracy of recalled information. The biographers also held different levels of experience in this role. Variability also existed regarding interviewing styles, rapport, and techniques, which were also influenced by the patient's demeanour. Nonetheless, the biographers influenced construction, but to what degree remains uncertain.

The significance of context was also exemplified in the tributes offered within these accounts. Every account included tributes to the Hospice for their palliative care:

The Hospice and the nurses, they're absolutely brilliant. .. I don't have pain or fear and if I do have any the Hospice will take it away from me
(Mark).

In addition, storying these accounts from a position of facing death would have held a significant influence. As Bruner (1990) pointed out, the narrator is not telling about the past, but rather, deciding what to make of the past narratively at the moment of telling. Hence, these stories will be guided extensively by the experience of facing death. Given these accounts were going to be presented to significant others, construction would have been mindful of their distress with positive attempts made to assuage this. As Lichter (1991) highlighted a common concern for the dying is how those left behind will manage their grief. This was echoed in the present study:

I don't want to leave anything behind that will hurt anybody
(Mark).

Nevertheless, we are not suggesting these biographies were fashioned for the express purpose of mitigating others' grief, simply this factor would have been a consideration and therefore requires awareness. Further, highlighting the presence of these factors is not intended to undermine the value of these accounts; rather to encourage being mindful of their presence in construction. As Denzin (1986) pointed out, the context in which personal stories

are created, the objectives associated with their creation and the audience to whom they are addressed, frame and mould their structure.

> **"Stories are necessary to weave a web of meaning within which we can live. We all live in story worlds."**
> *(Miller Mair, 1989, p. 45)*

FINDINGS

Analysis of Narrative

Narrative Typologies

Narrative typology is an important component of this analysis because the themes inherent within each type function as an organising principle in structuring the plot, and serve as a standard for highlighting certain events as more relevant than others (Hermans & Hermans-Jansen, 1995). Investigation of these biographies illustrated they all accommodated the progressive narrative with a range of sub-type patterns existing within this general form. Progressive narratives can be considered to form a particular genre of stories about living with serious illness in which the meeting of, and overcoming the physical manifestations of the disease is a key element (Freeman, 1993). The biographies storied lives organised around living with a terminal illness with a focus on goal realisation. Evidently, movement toward personally important life goals, regardless of actualisation, enabled meaning to be located in story.

Robinson (1990) asserted that personal biographies are likely to be written in a form which exemplify positive perceptions of lives with illness more frequently than previously indicated. The biographies in this study reiterated this. A common feature was the positive construction of goals constituted either prior to diagnosis or continuously reconstituted following this. With illness the nature of goals were modified accordingly; adopting simplistic, non-material goals and reordering priorities. Explicitly, adjusted goals concerned unfinished business, including organising funeral arrangements, creating legacies, locating origins, and attention to spiritual beliefs. Recognition of the finitude of life was responded to with goal focus narrowed from the distant future to the present, and the adoption of a philosophical attitude toward life:

> **Live every day as if it's your last**
> *(David).*

In addition, despite the losses imposed by their illness, there was a blatant refusal to ruminate over the unfair, indiscriminate nature of cancer. Considering the interpersonal context they were constructed within, this may have been the only possible story.

Mark produced two biographies, one concentrated on the experience of illness, the second explored illness and other events throughout his life. These were fashioned around positive progression toward personal goals. The illness account opened with a brief reflective overview exploring the limited exposure to illness throughout his life: *"yet here I am in my fifty-eighth year with terminal cancer."* This anomaly established the nature of this account: the biography was woven together by the thread of understanding the experience while moving toward this realisation:

> **Cancer is a very personal thing and I want to learn how I relate to it**
> *(Mark).*

Following diagnosis his storied life did not stop; instead goals were reshaped and based on completing unfinished business and leaving a personal legacy:

> **My three major tasks which were "must do's" were:**
>
> **a. to plan my funeral;**
>
> **b. to make some sort of record of my life:**
>
> **c. to write this account of my cancer**
> *(Mark).*

Richard's biography demonstrated a life directed toward important personal goals. Prior to illness onset the narrative proceeded favourably with intermittent setbacks. With diagnosis, goals were modified, concentrating on tidying loose ends. In this way the focus remained goal-directed:

> **When I realised the seriousness of my illness, my thoughts turned to settling my affairs and tidying up the loose ends of my life**
> *(Richard).*

Simon's biography was organised positively around efforts to achieve a simplistic goal: "peace of mind was my only goal in life." Throughout the story putatively negative events and experiences were surmounted despite painful consequences. Prior to illness this included endeavours to vanquish personal tribulations such as alcoholism and failed marriages. Further, when faced with cancer and the numerous surgical procedures, for example, bowel resection and nose amputation, the narrative concentrated on tasks he could manage, such as daily home executive duties, extracting beneficial elements from this experience. Finally, faced with a terminal diagnosis, a positive focus prevailed:

> **I'm classified as terminal but feel I am going to make old bones yet**

(Simon).

David's account presented a positive story directed toward goal attainment. Before the illness the story focused on career aspirations. With the disruption of illness there was a momentary interim where movement toward goals was stationary peppered by episodes of confusion and uncertainty:

> **I went through this period of thinking I'm never going to work again so it was a real grieving period. I had no goals and nothing to aim for anymore**
> *(David).*

In order to accommodate and overcome constraints imposed by the illness, the life scheme was changed with priorities reappraised, and simplistic goals adopted. A notable goal was the search into spiritual origins, a component which had been significant before the illness. Reordering priorities involved the development of non-material goals, a common feature of illness stories. Further, with imposed time restraints, the emphasis attached to realisation of goals became less paramount; partial achievement became equally important:

> **And then I stopped and thought about it and realised I had to have something to aim for even if it is for tomorrow**
> *(David).*

> **The drive is down, and it's not all that important if I don't get the workshop built**
> *(David).*

Margaret's biography presented a narrative which progressed toward important life goals. Unfortunately, this account was cut short by her death, precluding examination of goals following illness. Therefore the impact illness had upon the story's movement toward personal goals remains uncertain.

Elizabeth's typology represented a progressive narrative: organisation presented a positive progression toward important life goals. Throughout this account opportunities were utilised which facilitated or assisted the realisation of personal goals and aspirations:

> **The next step was snapping one's fingers at the illness and maximising the time one had left, living each day at a time and enjoying the simple pleasures of home, garden, shopping, driving and, above all, the company of treasured friends**
> *(Elizabeth).*

Evidently, despite illness these life stories focused on realisation of personally important goals. Goal selection was meaningful as it reflected making choices and taking action, a proactive response to negative experience. Commitment to these goals facilitated order and purpose, giving accounts direction: aside from sometimes ending before task completion, they closed looking positively into the future.

In addition, these stories also accommodate a number of sub-type narrative patterns within the progressive typology, including implicitly and explicitly heroic stories and detective stories. These stories exemplify distinctive movement toward goals in response to illness.

Episodes within these accounts mirrored the progressive implicitly heroic narratives. The goals positively reconstituted following diagnosis embraced an idealised response to illness with a modest understated style. For example, storying the ordinary success of life preceding illness highlighted the courage when faced with this experience:

> **I have a very positive attitude towards life. I know that I can't beat what I have and I'm not even sure that I can fight it. All I can do is keep positive and keep going until I can go no further.**
> *(Mark).*

An inherent characteristic of the implicitly heroic progressive typology is the narrator's concern for others. This was a frequent feature of these stories, particularly how family and friends would cope without them. Solicitous preoccupation was indicative of a self-effacing story where the needs of others were equally important, if not more, than the narrator:

> **I think it is important to see the needs of others and to respond in the best way you can**
> *(Richard).*

> **My purpose in life was to make my death acceptable to me and other people around me**
> *(Mark).*

In addition, offering advice to others was a predominant feature and motivation for the construction of these implicitly heroic accounts. This information was based on personal experience and offered to assist others in similar situation. Indicative of altruism, this illustrated a method of self-transcendence, in which reaching out beyond personal concern engenders self-understanding and connection with others. This also evinced finding transcendence by contributing something to world. In accordance to Baumeister and Newman (1994) this is a motive which influences story construction: telling stories which give a sense of being able to make a difference:

> **Maybe my writing will help my family and friends understand and maybe a fellow sufferer will find something I have written to be of assistance**
> *(Mark).*

Recompense of losses in these stories embraced the implicitly heroic typology. Losses from illness were overshadowed by focusing on other areas of life. The

disappointment associated with unrealised tasks was mitigated by the recognition of fulfilment:

> **As I look back over my life I think I've had a tremendously fulfilling life**
> *(Elizabeth).*

Losses were compensated and almost surpassed by gains in other areas of life. Explicitly this involved concentrating on positive aspects associated with cancer. With some accounts illness is perceived as offering an opportunity for inner growth where losses are reinterpreted as gains:

> **[discussing nose amputation] It did a wonderful thing for me. I grew to love people. I had been given the gift of love for which I thank God**
> *(Simon).*

> **It didn't take me long to work out that having cancer is a privilege. I could have had a sudden heart attack or been hit by a car and I would have missed all the opportunities I have to do things I want to do and say things I want to say to people I care for. That's another part of the privilege of dying the way I am because people get a chance to show it [their love] before you go**
> *(Mark).*

Illness expedited Mark's conversion described as: *"the happiest and most significant event in my life so far."* In this manner illness became personally significant, enabling suffering and death to be accepted because: *"life on earth is only one phase and the best is yet to come."*

Clearly these accounts did not deliberate on the losses imposed by illness; they preferred to concentrate on the gains associated with this experience. In this way the effects of illness were disregarded. Meaning was constructed by focusing on the positive, a method of meaning construction. Further, illustrations embrace the idea that suffering is worthwhile and purposeful, reflecting transcendence. As Frankl (1959) highlighted, the ability to choose one's attitude to an horrendous situation is vital, furthermore, it can never be taken away. One of Baumeister and Newman's (1994) motives also accounts for this type of story: people seek value and justification by constructing stories that depict their actions and intentions as right and good. Considering the interpersonal context this may account for the prevalence of the implicitly heroic story.

Another sub-type narrative pattern within the progressive typology was explicitly heroic. These stories present movement toward goals following illness, embracing an open and combative style. With illness, many accounts adopted a determined attitude toward this experience. Response to onset presented tenacious fighters, often reflecting the same vigour adopted before illness:

The way it is now, to put in my own words, God wants me to come but I don't - so it's under arbitration
(David).

So I decided well, there's only one way to treat this type of experience 'Right!' I thumbed my nose at it. I snapped my fingers at it. I said, 'if you want to make a meal of my bone marrow, make a meal and stuff off!
(Elizabeth).

This evoked images of courage: the illness course was opposed by the maintained capacity to battle on. Further, there was no indication of submission, indeed a resolute course of action was adopted. Albeit terminal illness has an relentless conclusion, the determined nature of these accounts reaffirmed the identity of victor. This proactive stance focused on attaining modified goals with an ardent refusal to concentrate on personal losses, exemplifying self-transcendence with the methods adopted when faced with something out of your control. The reaction towards illness was meaningful because this response remained with their command:

There had to be a refusal to dwell on the much loved Ph.D left unfinished, on being forced to leave the university, and not looking back at other forcibly relinquished activities which gave my raison d'etre
(Elizabeth).

Elements within Mark's illness account could also be categorised as explicitly heroic. The many invasive medical procedures enumerated before diagnosis projected a courageous individual. Similarly, despite the impediments imposed by illness the story focused on achieving personal goals. The narrative demonstrated a commitment to goals through challenging and attempting to overcome the physical manifestations of illness:

But it[cancer] is brilliant. It has got me off my butt and given me the sense of urgency I need to complete all my assignments
(Mark).

Explicitly heroic stories embrace one of Baumeister and Newman's (1994) motives in which narrators seek a sense of efficacy by making stories that contain information about how to exert control. These accounts may accommodate this progressive type of story perhaps because fighting illness may be the only course of action available to the authors.

Various accounts also embodied features of the progressive sub-type of the detective story. Robinson (1983) points out this is common when there is a lengthy period between symptom onset and illness, as evinced in several accounts. Illness onset facilitates an investigative quest for answers regarding the personal cause and a search for personal solutions regarding treatment. Evidence of searching for a personal cause in these accounts

was apparent. This is a recurrent method narrators adopted to make sense of illness within their stories:

> **I knew there was something wrong because I had symptoms of enormous tiredness. .. The breast cancer is quite unusual, so the surgeon told me. I had this group of knotted bloodvessels in my lower right breast for at least 6 years. To cut a long story short, the tumour made a meal of my bone marrow and that landed me in the hospital**
> *(Elizabeth).*

> **The benefit of hindsight tells me that the day I was passing blood was probably the day my right kidney gave up the ghost. I always presumed that the specialist had made more than a cursory examination of those kidney x-rays. I also feel that had I undergone an ultra scan at the time in conjunction with the x-rays the real problem might have been revealed**
> *(Mark).*

In this way the mystery is solved with the establishment of an onset. With regard to imputation, although the specialist was targeted, the story does not cast him as the villain; the story is more concerned with making sense of this experience than assigning blame. In contrast, with Murray's (1994) breast cancer accounts, blame was often attributed to the medical establishment.

Similar to biographies of this nature, this pursuit encompassed a search for a personal connection to the illness. Although no attempt was made to locate a cause, pinpointing the onset permitted movement toward integrating this experience into the storied life account. In contrast to most accounts, Richard's story ignored illness: the nature and effects of the illness were not investigated. Murray's (1997) breast cancer accounts also made limited reference to a search for a cause of their illness. This particular style of storying illness experience established an ingredient of mystery. In David's story the mystery was solved: the cancer was a result of exposure to abestos. Another component indicative of mystery was the uncertainty of remaining time: although certain that death is more imminent, the precise estimates for symptom development remain equivocal evoking a search for answers:

> **I guess it is the uncertainty of knowing at what rate the disease will progress - will I have another 3 years or am I going to live another 3 months? I guess this is something that I have to work through**
> *(David).*

This proactive search for information represented an element of reassertion of personal control in these storied lives. As Antonovsky (1987) asserted, even if the search leads to the realisation that one has little control, this is important; it is more important for things to be in control than under control. Investigative quests for answers established positive narratives, regardless whether explanations were established. Some of these accounts described illnesses with definite etiologies. Interestingly, those who could not or did not

locate a cause, traced the onset. With the benefit of hindsight narrators searched for a connection with illness in relation to their lives. In this way they could relate to this experience and assimilate it into their life story. Interestingly, searching for answers within illness narratives sometimes involve questioning whether the author is responsible for the illness and if one's actions are connected with the illness (Good et al., 1994). This was not evident within these accounts, maintaining the style of not allocating blame.

Robinson (1990) pointed out in his MS study the principal reason in continuing the narrative approach of the Detective story was the absence of clear etiology or therapy for illness. With the present study, although cancer has a more definitive etiology, various forms of therapy exist with divergent treatment responses. This may explain the adoption of this form by authors who searched for answers concerning personal treatment efficacy. With regard to personal solutions, different therapies were explored for evidence of efficacy:

> **If I start taking chemotherapy I'm going to be sick as a dog, whereas right now I just get a bit of pain so I just go and take some Panadol and I can carry on doing what I want to do**
> *(David).*

> **I've been put on a very good drug, an anti-oestrogene drug to which I've responded extremely well. That is the only treatment I'm having, that's the only treatment I want**
> *(Elizabeth).*

Making sense of proceedings associated with illness involved searching for answers. For example, accepting extensive surgical procedures involved rendering them purposeful through modifying perceptions of event; contemplating them as a method to eliminate cancer:

> **Unfortunately [surgeon] had to take away half the right side of my neck but I was free of the cancer, anything is worthwhile to get rid of it**
> *(Simon).*

In addition, questions regarding the fairness of illness and possible responses to this experience, are prevalent within detective stories: narrators generally ask "why me?" followed by "what can I do about it?" This theme of undeservedness was a frequent issue for narrators in Murray's (1997) breast cancer accounts. Similarly, other work such as Murray and McMillan (1991) commented on the popular belief of the unjust character of cancer. In contrast, these biographies did not ruminate about "why me?"; the inequity of cancer was only evident in one account and this was fleeting:

I have only once or twice had the thought that this [terminal illness] is a bit unfair. [age] is to me a bit young to be terminally ill
(Mark).

Alternatively, attention was concentrated on the latter question, "what can I do about it?" Specifically, when faced with illness the prevalent response embraced efficacious use of remaining time and pro-action:

One thing I've learned that if you intend to do something you've got to do it now
(Mark).

If what I was reading was true I couldn't have retirement at 65, then why not have it earlier. Let's stop work. Consult my doctor and convince ACC that they should support me. And so, we went from there (
David).

Personal loss associated with illness was recompensed by the forthright drive of the detective story. As Robinson (1990) points out, personal loss may be compensated for by the power and intensity of the story. Within these accounts the positive atmosphere overshadows surrounding losses:

It will always be a disappointment that I left a valuable piece of work unfinished at university. But one can't have everything can one
(Elizabeth).

Clearly, making sense of illness invariably lends itself to investigating illness, hence the adoption of the Detective stories. Investigating illness is goal-directed action, undertaken in order to understand this experience. Adoption of this investigative form of progressive narrative is meaningful because it facilitated making sense of experience, enabling authors to integrate this experience into a storied life.

Analysis of these accounts illustrated they were progressive narratives, accommodating other sub-type stories, the predominant being implicitly heroic and detective stories. In adopting this typology, accounts became very focused, revolving around goals which provided positive direction. The prevalence of the progressive structure in these stories reflects the broader context within which personal control over crises is promoted (Murray, 1997). As previously mentioned, the interpersonal context in story construction is very important and influenced the character of these biographies. Nevertheless, this narrative pattern appears to be a medium which permitted these lives to be storied in a coherent manner. Moreover, as Rosenwald and Ochberg (1992) highlighted, certain stories mobilise narrators to new actions, replacing existing meaning structures. Linked by the thread of

direction toward important life goals, the illness experience was assimilated and integrated into their life story. In organising their lives in this fashion meaning was constructed.

Narrative Devices

Given narrative is a valuable medium in meaning construction, investigation into inherent characteristics of this construct is important. Although there are many features within narrative, examination will be circumscribed, focusing on fundamental narrative devices which contribute to meaning formation. This will include: roles, epiphany, closure, and metaphor.

Roles

Selection of past thoughts are organised in response to current events (Barclay, 1994). Events which constituted this story were related to the endpoint (surmounting illness) (Gergen, 1984). Just as plot functions to select from many happenings, those which have a direct contribution to the story's ending (Polkinghorne, 1995), so do adopted roles. Roles adopted by the narrators determined what information was included making the story coherent and consistent. This involved selecting, rearranging, and organising experience into a cohesive order (Kleinman, 1988).

Examination revealed unfolding roles which mirrored the temporal nature of story. In line with Ricoeur's (1987) assertions, roles are deliberately selected and arranged to create a particular story. Roles were adapted to project the plot structure of these accounts. This encompassed disruption by illness, overcoming illness, and finally, surmounting illness. The various roles developed in accordance with this story were related to constraint, uncertainty, confusion, resolution, and overcoming adversity. Notable roles adopted by authors which warrant attention include those of victim, educator and hero/heroine.

With illness narratives the role of victim is often espoused. In these account this was infrequent; one author briefly adopted this during investigative procedures leading up to his diagnosis:

> **[prior to diagnosis] I resigned myself to endure whatever they [medical professionals] wanted to do in order to get me back to normal**
> *(Mark).*

This role maintained the progressive typology; adoption of this role was goal-focused as it was utilised to succour attempts at discovering the source of the problem. Further, relinquishing care to the medical establishment assigned responsibility and control of the physical component to another party, a proactive choice. This separation of physical body

from psyche is an important feature in illness narratives (Kleinman, 1988). In divorcing the diseased element, the self is separated, enabling the individual to preserve something of himself. Paradoxically, this allocation allows the individual to take control of the crisis; distance proffers a new perspective where the author is removed from the turmoil. This enables the narrator to rearrange experiences and events into a cohesive structure. Chandler (1990) emphasised the importance of narrative perspective in storytelling. Similarly, within Murray's breast cancer accounts, some survivors were quite self-conscious about the healing potential of perspective-taking within writing. Apparently role provides an opportunity to gain narrative perspective of author. Given these narrators are recollecting the past from the present perspective of facing death, they are trying to exert control over this crisis (Baumeister & Newman, 1994). This distance enables narrators to exercise control over the past (Bruner, 1995) by selecting roles which reassert control over the crisis. With the disruption by illness there was evidence of constrained roles, particularly regarding goal realisation. This intrusion in the storied lives is also accompanied by uncertainty and confusion:

> **forced to leave the university for health reasons ... forcibly relinquished activities**
> *(Elizabeth).*

> **I'm in a bit of a quandary at the moment. .. [postponing a holiday] I'll probably make the new year but then again how fit will I be?. So I am feeling in a bit of state of limbo at present and a bit frustrated and restless**
> *(David).*

Following the crisis the narrators change the plot lines through reconstructing their roles within the story. Explicitly, this encompassed heroic/heroine roles. Adoption of these roles present an idealised, courageous response to illness, which is focused on goal realisation. These roles project a story about overcoming adversity. Interestingly, this theme has roots in medieval prose where the journey of life involves trials and tribulations with heroic quests against good and evil. This dynamic of conflict produces tension in the plot creating a dramatic story which coerces action through change:

> **After I was diagnosed [wife] and I went through a really sad period. Then I stopped and thought about it and realised I had to have something to aim for even if it is for tomorrow**
> *(David).*

I've been put on a very good drug, an anti-oestrogene drug to which I've responded extremely well. That is the only treatment I'm having, that's the only treatment I want. There is no way anyone is going to shut me in an underground bunker with thick walls and then rush from the room! Also, I am not going to take and swallow any of their chemical cocktails - besides, I've got a 50 dollar perm now and I'm damn well not having that falling out! What a waste of money, for God's sake!
(Elizabeth).

Given the affirmative qualities embodied with the heroic/heroine role, this action will be positive, evinced in these accounts. Overcoming adversity was storied by adopting a positive attitude, accepting both the good and the bad encountered throughout life . This also involved refocusing on goals despite new obstacles imposed by illness. In effect this role is an impetus which reinvigorates the plot, realigning it back onto a positive trajectory. In adopting an heroic stance toward illness, the story is positively transformed with this conflict surmounted, albeit metaphorically:

I don't know how much time I have and I don't want to know. I'm just going to carry on living my life day by day until I can't do it anymore
(Mark).

A personal spirit which can laugh at life, sorrow at its mindless cruelties and perceive the inanities of human existence (
Elizabeth).

In addition, the role of educator was prevalent and deserves attention. As previously mentioned this was a significant motivation in constructing these accounts. Authors used narrative as a platform to provide others with an insight into experiences encountered throughout life. Principally this concerned the illness experience; encompassing issues about treatment, the hospice, and adjustment to death. These passages appeared deliberately contrived to target other sufferers and significant others in order to amend misconceptions and allay distress:

Immersed in the agonies of the stressful abortion controversy ourselves once, we feel we cannot advise anyone else, even in similar circumstances, what to do. All we can do is share our experience here
(Simon).

It is necessary to carefully weigh the pros and cons of buying more time on earth at such an excruciatingly painful price, depending on the type of cancer and its progress
(Elizabeth).

To me the most important thing is learning to read and write. If you can't read, you miss half of life. Honesty is the most important attribute a person can develop - you waste time in pretending
(Richard).

In fact you should welcome responsibility because that develops you. .. You should treat problems as treasures because every problem you solve you have acquired further skills
(David).

Given these accounts were being presented to others, incorporation of this role is perhaps not surprising. According to Baumeister and Newman (1994), motives which influence telling of stories include wanting to make a difference and a desire to pass along information. In this manner these roles not only create a unique story but also provide a valuable source of information. Therefore this experience was meaningful because it fulfilled motives beneficial to others. In addition, this promoted transcendence by contributing something to the world.

The presence of central actors enabled a coherent framework to be constructed within the story. By placing self as the central actor amidst events, interpretation is made easier. Through bringing order to random happenings these roles gave the story cohesion (Murray, 1997). An important prerequisite for establishing meaning is taking the individual's context into account (Baumeister & Newman, 1994). Role helps to convey the context within which experience occurred. With regard to meaning construction, this is not always clear in the midst of experience. Often looking back enables one to make sense of experience (Polkinghorne, 1995). Given stories are shaped by people's needs to make sense of their experiences (Baumeister & Newman, 1994), roles may effect this by clarifying experiences and events of the past, present and future (Hermans, 1995). Moreover, as meaning is produced through interpretation of experience, reconstructing roles may engender clarity, facilitating meaning construction. Through adopting roles in story the narrator understands the relationship among the events and choices of their lives (Polkinghorne; Rosenwald & Ochberg, 1993). Finally, in constructing roles which accommodate surmounting illness, roles transform a story about crisis into a positive account about overcoming adversity.

Bearing the interpersonal context in mind, for the benefit of the audience, it may have been important to adopt roles which make explicit the surmounting of illness. As Coffey and Atkinson (1996) noted, authors may locate their own actions within particular frames of reference. This does not suggest a deliberate manipulation of story, rather a means to convey the narrator is back on track, given the universal desire for the audience to understand and accept their death.

Epiphany

A generic element common to all stories is the epiphany; a turning point which engenders action and subsequent transformation (Murray, 1994; Plummer, 1995). As Frank (1993) asserted at the core of any narrative is an epiphany; moments that provide a possibility for change. Illness within these accounts became a significant turning point; all change revolved around this experience. As Chandler (1990) pointed out stories often focus on certain crisis moments as an attempt to bring order to chaos. Principally, diagnosis prompted decisions to be made to restore order in the story:

> **If suddenly hit me [diagnosis] I wouldn't get to see my grandchildren grow up**
> *(Mark).*

Turning points are characterised by decision, risk, acceptance of possible negative outcomes, and later validation of the decision (Denne & Thompson, 1991). An example within these accounts involved the selection of a simple treatment regime in favour of more severe therapy programmes. This decision was deemed efficacious; enabling the continuation of daily activities:

> **If I start taking chemotherapy I'm going to be sick as a dog, whereas right now I just get a bit of pain so I just go and take some Panadol and I can carry on doing what I want to do**
> *(David).*

This crisis engendered the realisation of limited time, creating a sense of urgency and tension. Individuals responded by seizing chances and opportunities and utilising time efficaciously. As Frankl (1971) asserted the prospect of death motivates individuals to respond to opportunities. Existentialists emphasise the awareness of finiteness of life constitutes a precondition for appreciation of life. A terminal diagnosis shocks individuals out of complacency of the assumed futurity of their existence. Following diagnosis there was a universal change in these stories with the adoption of a renewed appreciation of life. Similarly, Murray's (1997) breast cancer accounts documented transformed appreciation towards life. Further, with the present accounts the focus narrowed to the immediate as opposed to the distant future, promoting a renewed outlook. As Davies (1997) suggested, terminal illness provides liberation from the perpetual grind of working toward the future, freed from pressures to create long-term plans. This epiphany engendered transformation in the story, manifest with the emergence of a new beginning:

> **To live one day at a time; enjoy the moment**
> *(David).*

Let it [ordeals] all be ashes so the phoenix can rise
(Simon).

Negative events destroyed many individuals' worldview, prompting a search into other areas to assist in making sense of this experience. This quest lead to a spiritual resurgence to regain order and purpose in their storied lives. Admittedly, there was varying degrees of spiritual transformation; some underwent conversion while others moved toward re-establishing the importance of faith in their life stories. Regardless of the extent of change, this experience held a significant position in the accounts. This epiphany lead to a powerful shift in the story; not only had the story survived this crisis , but it was positively transformed looking forward:

I had been thinking that all there was to life must be getting up, going to work, coming home and going to bed. So when my marriage broke up my whole life shattered - all my ideals. .. I went back to looking at spiritual things
(David).

I decided then [when received diagnosis] and there that I would seek to be received into the Catholic Church. .. This turned out to be the happiest and most significant event in my life so far
(Mark).

Epiphany transformed the illness experience within narrative. Described by some as *"their greatest challenge"*, enumerated by others as a *"hugely emotional cleansing"*, these positive depictions modified the pernicious perception of this experience in story to one which provided personal rewards. In addition, this device also changed the individual in the story. The individual overcame personal crisis in the story by taking possession of the object which threatened to consume them - illness (Murray, 1997). Their character was modified from an individual stricken by an illness with a relentless physical course, to someone with the ability to relate to the world with a new approach (Chandler, 1990). In this manner, epiphany appears to be a narrative process which promotes challenging, overcoming, and becoming regenerated in one's story (Murray, 1994).

According to Ryff and Dunn (1985) almost every narrative contains some reference to the new person which illness has produced out of the old self. Frankl (1993) described this as a process of awakening and renewal, characterised by an ongoing process of personal assessment. Transformation in these accounts reiterated this. Illness appeared to be a permission-giving experience which produced cathartic response in the story. This facilitated open expression of previous latent feelings. Self-transcendence is mirrored through personal introspection; looking in within oneself to find increased self-awareness:

It's true to say that I have not wept for myself since [diagnosis] but tears can still come easily and when they do I let them go. I spent the first fifty years of my life bottling up emotion, now it can run free
(Mark).

Turning points have been highlighted as occasions for growth through crisis (Denne & Thompson, 1991). With epiphany the narratives were organised to redefine the crisis as an opportunity for rebirth and growth (Frank, 1993). Similarly, in Christian theology suffering is a common theme in religious stories of birth and rebirth (Kleinman, 1988; Murray, 1997). In this manner epiphany transforms a negative experience into one which is profitable and significant. This is a common feature in illness narratives, where narrators have delineated illness experience as necessary and valuable (Steeves, 1992).

With regard to meaning construction, given epiphany promotes personal growth through suffering, this mirrors self-transcendence. Frankl postulated the way an individual accepts their fate and the associated suffering, can add to a deeper meaning in life. Within these accounts, not only is the illness experience accepted, but is assigned a special position in the storied lives. An epiphany is meaningful because it effects making a choice and taking action. This was evinced in reaching decisions regarding treatment. In addition, given this was a personal choice arrived at in conjunction with relevant information, this illustrates the following motives which guide narrative in terms of wanting to make sense of experience. According to Baumeister and Newman (1994) narrators seek value and justification by constructing stories which depict their actions and intentions as appropriate. In this regard, with the treatment decision storied as a personal choice, this represents a legitimate foundation. This choice also reflects the motive enumerating the narrator's desire to sense efficacy by making stories that contain information about exerting control:

I had long decided beforehand that if ever I was singled out for this [illness], I would eschew chemical cocktails and being carved up on the surgeon's table. These decisions were not arrived at irrationally. In order to make them, cancer survival statistics needed to be studied
(Elizabeth).

Closure

Considering narrators look for closure when telling stories, it is important to examine how these accounts end in relation to meaning construction. Gergen and Gergen (1984) asserted storied accounts must establish valued endpoints, a point reiterated more recently by Kleinman (1988). Given these accounts were storied retrospectively facing death, the focus was on making sense of this experience. As Polkinghorne (1995) highlighted, stories are concerned with attempts to progress to a clarification of the present situation. The biographies started from the same point - "how I came to be where I am today?" (Coffey &

Atkinson, 1996), and ended at this point. The function of this story was the creation of a coherent framework; selecting from many happenings those which had a direct contribution to the story's ending. This was evinced in the exclusion of some events and happenings deemed redundant to the story:

> **[discussing what material to incorporate in account] you leave all the bad bits out (Mark).**
>
> **I have left out details which are very personal**
> *(Elizabeth).*

Closure promotes an organised structure which enables individuals to make sense of events and happenings with regard to the endpoint. An important issue apparent in closing these storied accounts was one of unfinished business; a pervasive theme in illness narratives, this provides some closure to storied life. Authors focused on clarifying *"loose ends"* in their lives, such as making amends. This is a significant element particularly when this cannot be physically remedied. For example, in the event where the concerned party is not available:

> **It took me until he [father] was well in his 70s to get to like and understand the man and eventually to love him. I'm happy I was able to him that I loved him before he died**
> *(Mark).*

Interestingly, this clarification was not always directed toward significant others: uncertain personal decisions and paths chosen during their lives were also frequently re-examined. Given this process is indicative of resolution, tidying up unresolved conflicts in storied lives appeared to facilitate closure:

> **Given another chance, I would try to be more open about any difficulties I was having, and not try to cover up (**
> *Richard).*

In addition, attempts to understand the illness experience represent a process toward integration and acceptance, indicative of closure. Further, this established the focus of many accounts and their ending. This device organised events into a storyline progressing toward clarification of an incomplete situation. In this respect closure facilitated the progressive nature of these accounts:

> **Cancer is a very personal thing and I want to learn how I relate to it**
> *(Mark).*

Terminal illness, like chronic illness, to a lesser degree, is one which the individual cannot put behind them. Although the time frame is more limited with the former, these individuals are compelled to construct a story which integrates the continuing process of this illness. As Robinson (1990) pointed out *"the storyline can transcend the advent of physical*

death" (p. 1176). Despite storying their lives from the perspective of facing death, they did not close in a sad, gloomy manner, resigned to defeat. Rather, they ended with a positive focus which continued to look ahead. As Murray (1997) highlighted, authors generally bring the story to a close with a happy ending. In accordance with their progressive typology, they ended at a point where important goals had been actualised or in the process of moving toward this. This was exemplified in one biography which closed with the inscription chosen for her epitaph, fostering a sense of satisfactory closure. Notwithstanding, death was imminent, their storied lives continued as if transcending this. In a sense the narrators prevail through their stories. Considering the interpersonal context these accounts were constructed within, perhaps this is the only possible closure available to these narrators:

> **Life on earth is only one phase and the best is yet to come**
> *(Mark).*

> **Home is the hunter, home from the hill, and the sailor home from the sea**
> *(Elizabeth).*

This creates a certain ambiguity within these accounts regarding closure: although the stories are physically closed, the ending is contrived in such a way that it engenders continuity. Williams (1984) pointed out, continuity is often created during efforts to reconstruct personal life stories which have been disrupted by experience. The manner in which these accounts were framed created continuity. Specifically, the temporal framework of storying the past from the present effects a focus into the future. Similarly, Plummer (1995) highlighted, a crucial strategy of storytelling is the creation of a sense of the past which helps to provide continuity.

Storying their lives in a coherent framework facilitated construction of a meaningful story; enabling narrators to assimilate illness into their life story and move toward acceptance of approaching death.

One biography poignantly illustrated this closing with a poem about acceptance. Others ended enumerating trials overcome, or just endured, reflecting illustrations of self-transcendence (Frankl, 1987). According to Frankl, when individuals are confronted by utter desolation and unable to express himself/herself in positive action, when the only achievement consists of enduring suffering in the right way, through this attitude they can achieve meaning. This was embraced in the following extract, describing an individual's attitude toward the illness experience with a commitment to the future:

All I can do is keep positive and keep going until I can go no further
(Mark).

As previously mentioned, closure is an important component for realisation of personal meaning and promoting death acceptance (Erikson, 1961). Meaning of experience is clarified by affording closure or a sense of completion in the life story (Lashley, 1993). In order to make sense of experience, it is necessary to resolve unfinished business; closure within these accounts involved resolution of unfinished business. Given death anxiety was a peripheral concern within these stories, establishing closure within storied life may have assuaged these concerns. As Lichter (1991) highlighted, the resolution of unfinished business is important for achieving a sense of completeness which promotes a tranquil death. Perhaps because these stories worked through personal issues, this was not a significant concern with these accounts. Just as working toward completion of tasks provided closure, clarifying personal issues in story may have reduced death anxiety:

things that would keep me awake involved working on my little tasks. My tape and my story and my funeral and I couldn't stop my mind working. But having completed those tasks I don't have those kind of things to keep me awake anymore and I sleep very well
(Mark).

Metaphor

Metaphor encompasses analogies, personification and other kinds of imagery. The metaphor serves a special purpose for the narrator. By using this device they convey an image; drawing in the analogy of a physical entity they liken their experience to other things (Coffey & Atkinson, 1996). In trying to explain complex constructs we often resort to metaphor (Romanshyn, 1982). Lakoff (1984) reports that metaphor serves an important mapping function in cognition by introducing information from the physical-world into the non-physical world. By drawing analogies from the physical experience, metaphors assist people in conceptualising non-physical processes in a concrete, visual way that makes those experiences more tangible and hence accessible to mental processing. Encapsulated by John Speirs' discussion on allegory: *"What was dimly thought or felt was made tangible or visible. The abstract made concrete. The barely intelligible made imaginable and so more clearly intelligible."* (1954, p. 27)

Quinn and Holland's (1987) review of studies found a small number of metaphor classes are used in describing particular experiences. With illness, Catani (1995) highlighted the challenge the narrator is faced with in finding words to describe their experience. Through metaphor narrators adopt a stance toward their illness by conveying this experience in a particular way.

Chandler (1990) emphasised the importance of this narrative perspective in their stories. In the present biographies, metaphor was used principally in discussions surrounding illness. This included imagery such as, nature, a journey, battles, in representing this experience. Interestingly, positive imagery was also adopted in these representations.

The illness experience was conveyed by an analogy to nature. Metaphor was of a living thing, sometimes explicitly equated to a plant:

> **Group of knotted bloodvessels in my lower right breast rooted there for at least 6 years. It didn't bother me and I didn't know about it, I was too busy**
> *(Elizabeth).*

Elizabeth used a plant metaphor to describe her breast lump, which she could not physically see or feel. In this way she created a set of images and characteristics that could be used to conceptualise this experience in a concrete way. Further, this construction imposed likely predictions: roots grow and disperse; spreading throughout the body (Quinn & Holland, 1987). Similarly, in Mathews et al (1994) advanced breast cancer study, the theme of plant featured significantly in interviews. Symptoms they identified also included descriptions of "knots." Further, resembling Elizabeth's account, the illness moved from being a static, almost non-living entity that caused no trouble or pain, to something animated that begun to take on a life of its own, growing rapidly and becoming bothersome. Analogy provided plausible mapping of a physical-world image onto the experience of tumour growth and represented a creative attempt to explain something for which they had no explanation (Mathews et al., 1994). In addition, the illness is presented as something alien which has intruded upon normal life. This may establish continuity in life: illness is conceptualised as something external to the continuity of her life (Hyden, 1995).

Several accounts equated life to a journey. Interestingly, given these accounts storied lives around travel, this appeared fitting:

> **The culmination of this extraordinary pilgrimage we all are on is death**
> *(Elizabeth).*

> **An escorted guide to my grave**
> *(Richard).*

As a narrative mechanism, metaphor enabled the reconstruction of this story as an expedition. This analogy furnished a variety of images inherent with travelling, including: turning points, barriers, breakthroughs, states of being lost and of finding oneself (Carlsen, 1995). These items shape how life is perceived: defining life as a pilgrimage implies direction, purpose and a end. This journey encompassed various encounters, both positive

and negative before arriving at this destination. In a sense this creates the impression of having reached the end. Concordant with Robinson's (1990) assertion, *"a personal story maybe ended before a life has physically finished"* (p. 1176). Accordingly, events and happenings within the story are invested with significance in relation to their effect on this quest. Reconstructing life in this manner instilled it with purpose and direction.

> **During my period of trial [following diagnosis]**
> *(Simon).*

In addition, medieval poems about journeys referred to constant paths or quests overcoming man's trials and tribulations. With reference to this analogy the quest is transformed into a grander, more noble journey of overcoming perils. In this way, the story becomes bigger than itself; it is lifted beyond the personal level, representative of Everyman's journey (Speirs, 1954). Descriptions of life as a trial also conjured up biblical references to Jesus being tempted in the desert by the devil; a period of personal adversity, which was surmounted. This analogy conveyed imagery of the difficulty of this experience for the narrator. Further, the metaphor of a quest, attached importance to this experience, something to be overcome, rather than something inane.

The metaphor of battle was a recurrent theme in these accounts. Interestingly, the most dominant theme adopted in cancer stories is that of a combative stance (Murray, 1997). In Susan Sontag's (1977) *Illness and Metaphor,* she presents the earliest semantic exploration into popular Western representations of cancer. Accounts she examined described cancer as a "secret", "ruthless" invasion which "invaded" their bodies (Donnelly, 1995). This analogy conveyed the battle between two adversaries - cancer and the self. This theme is prevalent within the present accounts. Titles such as *My Battle With Cancer* and *The Ugly Head Rears Again* echoed this as did the account describing *"being slain in the spirit."* Use of metaphor divorced the individual and illness creating a perspective of 'it' and 'me'. An unfolding drama ensues with a struggle between these distinct entities. In conjunction with medieval prose, battle involves a moral conflict of good versus evil; in this analogy, self versus cancer, respectively. Simon's extract presented cancer as a nefarious entity with invidious intentions which has invaded the body. Reference to a moral and religious conflict moves this battle from a personal level to one for humanity.

> **it [cancer] throttled the urethra**
> *(Simon).*

Similarly, Murray's (1997) breast cancer accounts adopted the combative stance toward their illness. Interestingly, these accounts were written by survivors, yet the present

accounts, storied by terminal patients, also adopted this perspective, albeit not as fiercely. Status did not seem to influence adoption of this combative perspective. In addition, Del Vecchio Good et al (1994) noted how oncologists utilised this analogy to promote hope in their narratives with patients. They choose metaphors of hope in attempts to engage patients in a struggle against death and disease with treatment. Adoption of the battle metaphor is used to portray a struggle with illness (Balshem, 1991) in which an active response is demanded (Donnelly, 1995). In a sense distance is produced from the crisis, permitting the narrators to assert control of the crisis, in effect overcoming it - metaphorically.

This introduces the concept of the mind-body dichotomy, an important feature in illness narratives. According to Western society the body is a discrete entity separate from thought and emotion, creating a dichotomy of body and self (Ware, 1992). Mind-body dualism pervades much of popular and professional discourse about illness (Johnson, 1987). Within this cultural schema, illness is reduced to a malfunctioning part - separation, with an internalised relationship between illness and individual, self opposed to illness. In the experience of illness, symptoms are distanced: the individual recognises that he/she has a sick body which is distinct from self, alienating the illness from the individual (Kleinman, 1988; Ware, 1992).

By utilising metaphorical imagery to contrive a storied account which accommodates the transformation of identity from a victim role to that of opponent, the narrator adopted an offensive toward the illness. As Murray (1997) points out in his study of breast cancer survivors, the act of writing about the experience allows the narrator to separate themselves from this invader of their bodies. Talking about illness as something extraneous, something that has invaded one's life from the outside (Mathews et al., 1995).

Another metaphorical device, personification was utilised within stories to distance narrators from the illness. Given Elizabeth's cancer was not directly attributable to external influences, for example, sun, toxins, this representation was adaptive in disconnecting the physical manifestation from within herself. Further, assigning cognitive abilities to this entity removed personal responsibility. As Johnson (1987) pointed out, to have a legitimate complaint is to have one ascribed to the body, to an underlying organic disease for which the sufferer cannot be blamed:

The tumour they [blood vessels] grew decided it [cancer] would make a meal of my bone marrow. So, it had itself a little main course, and that landed me in hospital
(Elizabeth).

As the narrator, Elizabeth storied this experience as an onlooker with symptoms independent from herself. Kleinman (1988) reiterated this; describing individuals relating to their illness experience as an observing self. This dichotomy was also evinced in many accounts describing the care furnished by the hospice: separation was explicit by assigning care of their physical body to hospice while the self remained under their management. In this way the self has circumvented the influence of illness. Mind-body dichotomy views the ill body both as object in need of being fixed and as an obstacle that constrains and opposes self (Garro, 1994). Illness forces an awareness of the body as separate from self:

There's time to put our house in order, our spirits, our minds, but not our bodies which are under Hospice care
(Simon).

I don't have pain or fear and if I do have any the Hospice will take it away from me
(Mark).

Metaphor was also employed to emphasise the importance of acceptance of illness, associating refutation with the imagery of drowning. Reference to tide is indicative of an unchangeable course: although possible to swim against the tide this involves a continuous struggle. Further, similar to the constant course of the tide, terminal illness is irreversible. Finally, the two tidal directions mirror the decision choices with the issue of acceptance: accept or refuse, the latter described as futile. Metaphor was applied to restory her acceptance of illness as reasonable, legitimising this action: narrative facilitated meaning by making sense of this resolve:

Those of us [terminally-ill] must decide to swim with the tide of events which has now engulfed us
(Elizabeth).

Metaphor appeared effective in reframing one's viewpoint, evinced in the biography felicitously titled *My Brilliant Cancer*. This facilitated the remaking of his life story in which this experience became a very personal one. Similarly, the experience of suffering concomitant with illness is reconstructed through metaphor. Enumerated as a diamond, this analogy conveyed positive qualities of becoming a better person through transformation. The narrator adopts this analogy to conceptualise this experience in a positive manner:

The heart is like an uncut diamond and every time you suffer it's because someone is cutting a facet on the uncut diamond. The more you suffer the more that rough diamond is being cut
(David).

Loss is a significant element for those who experience illness. Charmaz (1983) described the loss of self in connection with chronic illness, and particularly the dying (Lichter, 1991). This includes a variety of factors including: lifestyle restrictions, loss of independence, loss of job and status as wage earner, and attractiveness (Curbow, Legro, Baker, Wingard & Somerfield, 1993). Added to the loss of control over external events is the loss of bodily control. These threaten individuality, identity, competence and life projects. Perhaps being able to divorce the illness and their psyche may enable them to preserve something intact, untarnished by the cancer, retaining an element of himself/herself which existed before the onset. In this sense metaphor facilitates meaning construction: despite loss of their physical being the self can continue:

My body may be affected but my brain is intact
(Mark).

The use of metaphor in story created a very powerful story rife with vivid imagery. Adoption of this device presented a multitude of avenues for interpretation with a foundation in everyday and medieval prose. The narrator's interests were served by using metaphor. Metaphor enables narrators to make sense of this experience through comparison to characteristics based in cultural schemas of illness. This conveys an image of their experience as one in which they have asserted control over crisis. Further, through analogy the narrator reconstructs this experience as one which possesses positive qualities.

With regard to meaning construction, the metaphor was used by the narrator to make sense of experience within their account This device enabled narrators to establish distance, an important quality which helps to reframe perspective: clarity enables personal significance to be attached to experience and events (Mishara, 1995). Metaphor accommodated the separation of mind and body and these stories were built around this. Choosing to assign their physical care to external party was made sense of by separating their body from the self. Self is constructed as an entity which remains within their domain, facilitating control over crisis. In this manner, narrators have used metaphor in their stories to depict their actions as correct in order to seek value and justification. Metaphor was also utilised to create a sense of efficacy in their stories by demonstrating individuals exerting control (Baumeister & Newman, 1994). Given the interpersonal context these accounts are constructed within, the narrators utilise metaphor to promote control over crisis within story.

Storying Meaning

This study is interested in how meaning is constructed through storying a life facing death. Storying meaning has been chosen as a means of making sense and showing the significance of thoughts and actions in the context of an unfolding plot. This offers explanatory knowledge regarding the processes of meaning-making in these stories.

The plot describes meaningful lives that are interrupted by adversity, which manage to overcome this. Interestingly, Waitzkin and Magana (1997) highlight that patient narratives tend to be interrupted by negative events. The majority of these stories are simple, encompassing one major disruption by illness. However, several accounts are more complex involving multiple disruptions. Regardless of the number of interruptions, these difficulties are surmounted in these stories. Prior to disruption(s), these stories are replete with sources of personal meaning. Singer (1992) highlighted that thinking about death reflects what we consider meaningful in life itself. This included elements such as faith, family, friendships, accomplishments, travel, employment, and nature. These categories of sources have also been found by Reker and Wong (1988) and others across a variety of populations (De Vogler & Ebersole, 1983; Ebersole & de Paola, 1987; Reker & Guppy, 1988).

For the majority of stories faith occupied an important position in these accounts:

> **My faith has always been very important to me. My parish and my church are my whole life**
> *(Margaret).*

> **The Catholic Church is part of my heritage and is a great part of our lives**
> *(Simon).*

These stories also highlighted the importance of family:

> **He [son] has given me a particularly wonderful fulfilling life. As everyone knows, our children give us so much pure love. Their affection knows no bounds**
> *(Simon).*

> **Ours was a very happy compatible family with very little money but lots of love amongst us all. There were no fights, not even amongst the boys - we all seemed to work and have many happy times together**
> *(Margaret).*

Episodes throughout these accounts illustrated the significance of friendships:

> **Learning to live on the lifestyle [unemployment benefit] I got by because I had friends**
> *(Mark).*

Personal accomplishments were also enumerated as a valuable source of meaning:

> **I decided I would go to University where I spent the last 20 years on and of. Twenty years - the happiest years of my life, apart from my travelling years. I managed to accumulate three degrees and wonderful, wonderful friends. And a very full and stimulating intellectual existence**
> *(Elizabeth).*

> **When I left Britain, I told my friends that if I ever came back, I would have at least $2,000 in my pocket. I was very proud of the fact that I had come as a migrant, and now I was going back, paying my own way, and with plenty of money. The trip was the highlight of my life**
> *(Richard).*

Travel was another important feature:

> **The highlight of this trip [excursion trip] was for me going to Rome. It was absolutely wonderful! I was able to go to St Peters and hear mass by Pope Piux XII. When the Pope was carried into St Peters he passed so close to me I could have reached out and touched him**
> *(Elizabeth).*

Employment was predominant source of personal meaning in these stories:

> **As I was still partly supported by Social Welfare, I came under their jurisdiction ... I was becoming very tired of having to account for everything to Social Welfare but that required earning enough money to be independent. I managed to get a part-time job ... this lead to a full-time job. At last I was free!!**
> *(Richard).*

> **I got the only vacancy in the literary department, as woman's editor. And to be a woman's editor, even of a provisional paper at the age of eighteen was quite an onerous job**
> *(Elizabeth).*

Finally, nature was another illustration of personal meaning:

> **People complain that it is always raining when they visit Milford Sound, but I found it extremely beautiful, perhaps because of the rain. The lowering clouds looked like an endless line of torn lace curtains**
> *(Richard).*

> **I shall never forget flying over the Aegean Sea, and the islands down below with their little strings of light, it was like diamonds in a black velvet box. It was the most beautiful sight**
> *(Elizabeth).*

These stories present interruption by illness (and a range of other disruptions) with evidence of loss of meaning. Disruption of goals which had previously given a sense of purpose in life, resulted in feelings of meaninglessness and lack of purpose (Coward, 1990).

I was highly annoyed and frustrated that it [cancer] had taken away my meaningful existence
(Elizabeth).

Then it all crashed. That fatal day, I took my first drink
(Simon).

Ill-health forcibly rearranged one's life
(Mark).

[loosing custody of children as result of alcoholism] My precious sons stripped from me 12,000 miles apart
(Simon)

So when my marriage broke up my whole life shattered - all my ideals
(David).

[attending charismatic mass where individuals invited to be prayed over] I reckoned I was too tough to be slain in the spirit. I said they'll never do that to me, but I was proven wrong. Father was praying for someone alongside me but I was the one who was slain in the spirit
(Margaret).

When it happened [dismissed from job] I was devastated. I felt as though my life came tumbling around my ears
(Richard).

These extracts reflect shattered assumptions about the world, an inherent feature within Thompson and Janigian's (1988) Life Scheme Framework. With disruption, actualisation of goals fundamental to stable assumptions were threatened because illness (and other events) made it difficult to achieve these (Haberman, 1995).

Charmaz (1991) noted that serious illness changes the foundation of lives because it creates new and qualitatively different life conditions. Previous patterns of behaviour and lifestyles are no longer viable; they belong to the period of life prior to the disorder (Garro, 1994). Therefore individuals may be unable to participate in activities they depended on to provide meaning and purpose in their lives (Coward, 1995a). In these stories, the range of options available to the individual no longer seemed as wide and varied:

Lots of things I could do before [prior to illness] are no longer possible
(David).

forced to leave the university for health reasons, I had to give up activities which gave me my reason to live
(Elizabeth).

Predictability is essential for maintaining a stable world view and personal assumptions within the Life Scheme. Assumptions about the person and world were

questioned by the illness: it no longer seemed feasible to believe that one could control what happens through their own behaviour (Janoff-Bulman, 1992). This destroyed the stability needed to function in daily lives. When stability is threatened, life is disrupted (Thompson & Janigian, 1988).

> **[questioning diagnosis] I was bought up to believe that you always looked after yourself and controlled your own fate**
> *(David).*

Cancer introduces a fundamental sense of disruption into individual's stories by destroying the taken-for-granted futurity of their existence (Davies, 1997). In addition, with terminal cancer, although the life expectancy is significantly reduced, the exact time when death will occur is not precise, creating uncertainty:

> **I am feeling in a bit of a state of limbo at present .. It is the uncertainty of knowing at what rate the disease will progress - will I have another 3 years or am I going to have another 3 months?**
> *(David).*

Difficulties imposed by the disruption(s) compelled the need to re-evaluate views and activities which formerly gave these stories purpose and meaning. These accounts show abundant evidence of searching for meaning. This encompasses a number of methods including: attempts at making sense of illness (and other disruptions); changing the life scheme; and changing one's perception of the disruption(s).

When faced with serious illness an individual is coerced to uncover the meaning of the disorder and its consequences within the context of their life (Polkinghorne, 1995). Hyden (1997) commented those afflicted with illness seek to understand the causes and relate the illness to their personal lives. People make sense of their ordeals to give meaning to their experience (Luborsky, 1993). The narrative is effective because it constitutes a kind of causal thinking; the story attempts to explain lives and explore difficulties (Sandelowski, 1991). It is a medium for discussing possible explanations and perhaps a way of relating to this illness. In this way physical symptoms are transformed into aspects of individual's lives and diagnoses attain meaning within a framework of personal life story (Hyden, 1997).

> **Cancer is a very personal thing and I want to learn how I relate to it**
> *(Mark).*

These stories reveal evidence of a cognitive search undertaken to explore the nature of illness to promote an understanding of this experience. Causal searching is prominent within illness experience (Murray, 1994; Pennebaker, 1990). In order to make sense of

illness these stories explored information surrounding etiology, nature of cancer, and treatment:

> **During the original bowel operation they had taken out the lymph glands to stop the cancer growing but a speck remained in the lymph nodes and had been growing there for about 5 years. It had throttled the urethrea, the drain blocked and stopped one of the kidneys from working properly. The cancer is in the left lobe of the liver now and the right kidney is very weak**
> *(Simon).*

Donnelly (1995) noted that a person may be held responsible for falling ill through such things as an unhealthy lifestyle. In these stories blame was not assigned, or responsibility accepted, as this could not change anything and was therefore deemed a pointless exercise:

> **She [wife] spent years trying to get me to stop smoking because of the dangers of lung cancer. She found it hard to believe that my lung cancer emanated from my kidney. In the end it doesn't really matter wherever it came from it's still going to have the same result**
> *(Mark).*

These stories described coming to terms with this experience. This involved exploring the physical manifestations of illness in order to make sense of the impact of this experience:

> **I'm finding that I get tired a lot more quickly now especially when I am working around the property .. I'm finding I'll sit down to watch the news and end up dropping off which I've never done before**
> *(David).*

> **I physically felt the cancer move from my left lung so I now have it in both lungs**
> *(Mark).*

> **Although the doctor never told me, I was sure, from all the reading I did, that I only had about 8 months to live. It's generally accepted that mesothelioma progresses quite rapidly**
> *(David).*

> **If concern for my well-being could have saved me then the doctors would have pulled it off, but I was too far gone when I reached them**
> *(Mark).*

Garro (1994) argued that searching for answers regarding treatment helped make sense of this experience. This was clear in the present stories:

I accepted it [nose amputation] because the plastic surgeon told me that, provided I had 2 cancer free years, he could build another one
(Simon).

I had the choice of having a lung and diaphragm removed but the prognosis was worse than the disease. The second choice would have given me a better quality of life. So I decided to go for the second choice
(David).

The idea as I understand it was to drain off all the fluid .. which would make my lung adhere to my chest cavity again
(Mark).

These accounts also make sense of illness by interpreting death as a fundamental part of life. Lewis and Butler (1974) proposed that death may not be as threatening for those who view the fundamental meaning of their lives unaffected by it. Schaefer and Coleman (1992) argued in their HIV study, that perceiving difficulties in terms of fate makes life comprehensible. Given life events in these stories were interpreted in accordance with one's world view, this view accommodated illness as losses were perceived as a natural part of life:

For life is full of losses, little wonder, then, that the final loss is one's own life
(Mark).

We are mortal beings frequently at the mercy of our genes and a hostile environment. We literally dice with death from the day we are born. "Why become so permanently angry, appalled, terrified, defensive or self-pitying when a perfectly natural process catches up with one?"
(Elizabeth).

Aside from illness, other negative events were also explored in these accounts to make sense of this experience. As previously mentioned, meaning is not always clear in the midst of the experience, rather it was in looking back that an understanding of these disruptions unfolded through these stories (Mishara, 1995; Polkinghorne, 1995).

When we started out [initial divorce proceedings] this was going to be an amicable split, but in the end it turned really nasty and I saw a side of myself then that I don't ever want to see again. It was frustration on my part
(Mark).

[wife] was isolated here; she was used to a big place back home and I never realised that she was very lonely in the house. It was a big cultural shock for her. All the fears she had during the pre-natal experience of [son] together with the isolation, were too much for her and she had a breakdown
(Simon).

Another method to construct meaning in these stories was to change the life scheme. Modifying one's life scheme to ensure goal actualisation was a tangible method to secure meaning construction (Thompson, 1985). According to the Life Scheme Framework it is

important that acquisition of goals remain possible as this allows life to continue to be interpreted as meaningful. The significance of this was evinced in these stories where physical manifestations of illness precluded goal realisation:

> **Although I it's no longer possible to finish my PhD, I'm still carry able to give a few lectures on [subject] around the place, which I enjoy immensely**
> *[Elizabeth].*

In order to accommodate the temporal constraints imposed by illness, simplistic goals were adopted. Carter's (1993) cancer study highlights the shift in life goals to accommodate the changes imposed by illness. In these current stories, personal views on the future narrowed to present day:

> **After [diagnosis] I went through a period of real grieving - thinking I would never go to work again. I had no goals and nothing to aim for anymore. Then I stopped and realised I had something to aim for even if it is for tomorrow**
> *(David).*

> **Not knowing how much time I have I should perhaps, live by the philosophy I've quoted to other people I guess, live every day as if it's your last**
> *(Simon).*

> **To accept these realities [life is finite] eases the transition from this uncertainty to the acceptance where a temporary existence is acknowledged**
> *(Elizabeth).*

The universal adoption of the goal of "living one day at a time" was meaningful. Given the nature of this goal, implications imposed by illness could not preclude its realisation. Thompson and Pitts (1993) identified the importance of this type of goal in helping to continue to offer a sense of purpose and direction in individuals' lives. Developing a "here-and-now" focus was also evident in Moch's (1990) breast cancer study and Schwartzberg's (1996) HIV study, allowing a greater capacity to appreciate life in the moment.

Reordering priorities in these stories was another important mechanism to ensure meaning construction:

> **Suddenly it became clear that this was a good way to dispose of the money in England. I could give it to my old friend, not later, but right now. [depositing money into friend's account] was accomplished and I received his delighted phone call, so it gave pleasure to both of us**
> *(Richard).*

Pursuit of meaningful plans and commitment to goals was a prominent feature in these stories. Actioning important decisions also featured in these stories. This promoted

order and purpose, fundamental components for finding meaning. This was similar to findings in Davies' (1997) HIV study:

> **We've replanned a trip for both of us [David and wife] so now it gives me a bit more focus because that's what I wanted to do (**
> *David).*

> **That [anti-oestrogen drug] is the only treatment I want. I had long decided beforehand that if I ever was singled out for this final challenge in my life, I would eschew chemical cocktails and being carved up on the surgeon's table. These decisions were personal and were not arrived at irrationally. I have always felt that I would leave this dimension intact, just as I arrived in it**
> *(Elizabeth).*

Personal goals were concentrated on within these stories. Illness compelled addressing important tasks which typically revolved around the issue of closure:

> **[discussing organising personal funeral arrangements] To me, it is so important where one's earthly body ends up and mine will rest in a beautiful lawn, facing the hills and sun, near a tree where the birds sing daily**
> *(Elizabeth).*

> **When I left hospital I set myself three goals: one. I wanted to create the story of my cancer. two. Plan my own funeral. three. Make tapes about my life**
> *(Mark).*

A personal goal concerning closure involved locating one's origins. Lifton (1968) described this as symbolic immorality in which the individual facing death needs to maintain an inner sense of continuity. Working toward this task provides a sense of identity and accomplishment. This also produces a form of legacy, ensuring one is not forgotten. This echoes one of Frankl's methods of self-transcendence: giving to the world through creative works:

> **I want to get into my genealogy and the heraldry, and I want to do it myself**
> *(David).*

Similarly, another important personal goal associated with closure was leaving a legacy. In illness narratives where individuals are faced with death, the proclivity to leave something tangible of oneself is common. Evidently, the stories are tangible monuments of the narrators which transcend their death. Moreover, telling establishes a kind of final capability to permit the giving of advice, and to reaffirm bonds with those who will carry on the account after the narrator's death (Kleinman, 1988). Coward and Lewis's (1993) AIDS study highlighted the need to be known by others. The physical record of the account emphasises the worth and value others place upon them (Lichter et al., 1993). In this way,

the telling of these stories affords meaning in promoting closure, legitimising one's life, and promoting a sense of continuity:

> **I can leave behind the sound of my laughter**
> *(Mark).*

> **So if I don't leave anything else behind, I've left that [biography] and if other people are taking comfort from it that is my reward**
> *(Mark).*

Attainment of selected goals provide a sense of meaning and purpose. Considering the physical limitations imposed by illness, these accomplishments are judged by separate standards (Garro, 1994). In this way accomplishments following illness are invested with greater significance:

> **After 2/3 days of this [radiotherapy] I cooked dinner one night, the next night pulled a diseased apple tree and cut it up and the following morning dug up a tree and replanted it**
> *(Simon).*

This also encompasses acknowledgement of previous achievements. Given these interpretations are made facing death, earlier accomplishment(s) are invested with special meaning. Further, focusing on the highlights of life may enable the losses imposed by illness to be integrated, regaining a sense of meaning in life:

> **My one great ambition has been realised - to eventually die an educated woman!!**
> *(Elizabeth).*

> **Whatever the cancer person's philosophy, those of us over 60 have much to be thankful for if we can point to significant past achievements and the surmounting of challenges which may have proved too daunting for others to even contemplate**
> *(Elizabeth).*

> **But as I look back over my life I think that I've had a tremendously fulfilling life. I've had many adventures. I've been in places historical when great events have taken place and I also travelled the world when it was safe to do so as a young woman alone. So I've been very, very fortunate**
> *(Elizabeth).*

Where goal realisation was precluded by illness and other disruptive events, these stories adopted processes of meaning making to make sense of losses and regrets. One method involved investigating spiritual doctrines which could accommodate changes imposed by these events. The adjusted personal view promoted meaning, with the need to achieve no longer paramount:

God with his merciful eyes does not regard what you are or what you have been - but what you would be
(David).

In these stories, various methods of doing, such as commitment to creating something and carrying out unfinished business, produced meaning. Davies' (1997) HIV study also noted similar modes of regaining meaning. Although goal actualisation was important, the emphasis was on attempts to accomplish this rather than achievement per se. Therefore goals, irrespective of actualisation were vital for construction of meaning in these stories; they created order and purpose.

Stories described many experiences of finding meaning through various methods of self-transcendence. Frankl (1964) postulated that extremely negative events can be tolerable through sources of personal meaning, for example, spirituality. However, he believed these moments of comfort do not establish the will to live unless they help make larger sense out of apparent senseless suffering. In these accounts illness was placed within a spiritual framework and interpreted as part of the scheme of things. This response was meaningful as it located a sense of purpose in their suffering. Illness takes on meaning as suffering is mediated by cultural symbols of a religious kind (Kleinman, 1986). Specifically, the traditional Christian theology where suffering is not disvalued is evinced here:

[following separation he came across a book concerning new spiritual movement] Here were people who were talking things that I recognised, things that I had thought but been unable to discuss with other people
(David).

[during alcoholism]I decided to ask Jesus into my heart. I became fulfilled, I was no longer lonely, I was absolutely happy as I am today
(Simon).

[meeting priest in hospital] he anointed me and took away my sin. I swear I felt all the years wash away and it was a hugely emotional cleansing
(Mark).

I am healed. You see the wretch I was, and I am healed. Fortunate indeed. My faith in Jesus all these terrible years strong, wavering, strengthening till that great moment he took pity on me .. releasing the holy spirit to me
(Simon).

In these stories meaning was also found in one's attitude toward a unchangeable predicament. This was evinced in the attitudes demonstrated toward illness. Frankl (1969) highlighted this situation remains as opportunity to determine the manner in which one faces adversity. In this way, purpose was established in suffering with the freedom to choose one's reaction to this experience:

In order to do this [adjust to illness] you have to adopt a very positive and realistic attitude toward illness
(Elizabeth).

[discussing relinquished project] it will always be a disappointment that I left a valuable piece of work unfinished at the university. But one can't have everything, can one?
(Elizabeth).

Another illustration of finding meaning through self-transcendence, involved being open to receive help from others. In these accounts, this was exemplified in the receptivity to hospice care, others' generosity and appreciation of the physical environment - nature:

I've always been a giver and receiving used to embarrass me, but now I accept their gifts. My whole life since I left hospital really has been a series of receiving gifts in many ways
(David).

Other methods of self-transcendence involved moving beyond concern for the self, focusing on others, and looking inside oneself to experience increased self-understanding which promotes a connection with others (Coward, 1995a). In making an effort to reach out to give assistance they found comfort and purpose. By viewing their illness (and other disruptions) as experiences to help others, and make a difference, meaning was found in adversity. Present stories described a deeper sense of solidarity with other people through their struggle to regain meaning. Consistent with previous studies (Coward & Lewis, 1993; Davies, 1997; Schwartzberg, 1996), this culminated in a greater sense of belonging:

[discussing personal experiences in singles group meeting] I still succeed in making one or two people cry. Something I say must strike close to home
(Mark).

[following marriage dissolution, he discovered a new spiritual movement] I came across this book and I sat down and read it cover to cover that night and it rang a bell for me. Here were people who were talking things that I recognised, things that I had thought but been unable to discuss with other people
(David).

I looked inside myself and realised what I was. At last I accepted I was an alcoholic. I knew at last what I was and I wasn't alone anymore
(Simon).

Maybe my story will help a fellow sufferer to find something I have said to be of some assistance
(Mark).

I studiously avoided doctors all my life. .. I no longer have any fear of the medical profession. I have nothing but the profundest respect [for medical staff] who treated me with love, humour and dignity during my trial and although it is only just beginning, my association with Te Omanga Hospice assures me that there is much more love and dignity to come
(Mark).

I'd like to try and get up a lot earlier because that is the most beautiful part of the day where we are but I sleep in! Often early in the morning when the sun rises there are no clouds in the sky and the wind is still but come 9 o'clock the cloud starts drifting in and the wind gets up. There have been days when it is kind of cloudy and misty and it is beautiful also
(David).

Meaning was also established in the storied accounts by recognition of preserving human values and ideals. Living according to one's personal views was rendered meaningful. Self views were consistent with setting and obtaining goals. This restored meaning by actioning goals in accord with self view. This experience reflects one of Baumeister's needs for meaning: the need to find firm criteria of right or wrong used to justify one's actions and provide a sense of being a good and moral person. These accounts explored experiences following illness which accommodated living according to one's personal philosophy. Further, this was indicative of achieving a sense of exerting control over one's life:

Mine is the philosophy of an individualist. I have to live with myself in good conscience. This means thinking and acting according to what my reason convinces me is right. It means not following the crowds or conforming to organisational pressures however easy or safe those habits may be
(Elizabeth).

Another method to regain meaning involved changing one's perception of the negative event. According to Thompson and Pitts (1993), assumptions which generate positive interpretation of events or its consequences make it easier to find meaning because this presents less of a challenge to one's sense of meaningfulness. Meaning is a cognitive concept which permits individual to interpret experience in a variety of ways (Reker & Wong, 1988). Accentuating positive aspects of negative events is a common strategy in illness studies (Curbow et al., 1993; Taylor et al., 1983). These stories reveal processes of regaining meaning by focusing on positive repercussions associated with putatively disruptive events:

It didn't take me long to realise what I had was actually a privilege ... what I have with cancer is time. It gives me time to right wrongs, nurture relationships and help ease impending grief
(Mark).

The one great privilege cancer patients have is to tidy their affairs
(Elizabeth).

I didn't realise that so many people cared about me and that's another part of the privilege of dying the way I am because people get a chance to show it before you go
(Mark).

Framing life in this manner allows interpretation of life from various positions. In this way positive considerations could emerge from suffering by changing perceptions of the event:

The heart is like an uncut diamond and every time you suffer it's because someone is cutting a facet on the uncut diamond. And so more and more the divine light begins to be reflected in the heart
(David).

I accomplished exactly what I wanted to accomplish except my illness has forced me to leave my PhD unfinished
(Elizabeth).

[following disruption with loss of employment] I found another better job which made me feel as though I was a part of the organisation with my own little role to play
(Richard).

A further method of reframing life is to interpret inherently negative experiences as providing lessons, which engenders positive interpretation of experience. Moch (1990) argued that illness provided an opportunity to learn. This was evinced in the present accounts. Acquiring important lessons from difficulties is a beneficial strategy (Thompson, 1985). Meaning was found in negative experience by highlighting the fragility of life and the often uncontrollable nature of events:

If you're not struggling in this life you may as well join me in the next because you're not learning anything
(Mark).

[miscarriage] was a blessing in disguise as it made me realise that you can't plan everything - sometimes you have to take some risks and make a step
(David).

Finding benefits was also another mechanism for reframing life disruptions in order to regain meaning in these stories. Construing benefits is a common method individuals adopt in response to cancer (Donnelly, 1995; Haberman, 1995).

It [cancer] sort of focuses your mind a bit because we all have things we intend to get around to doing one day and alot of people never get to do them. It enabled me to think of things I had to do before I go
(Mark).

Everything's a blessing in disguise sometimes, even terminal cancer that gives time to put our affairs in order without haste. There's time to mediate to be at peace to rest and be thankful for the blessings of cancer. A sudden death you've been spared where time has disappeared
(Simon).

A prominent illustration of construing benefits from illness experience involved rekindling spiritual beliefs, an element which proffered fulfilment in many lives:

I go to mass every day now to sustain me; since I became a house-husband [with illness] this is one of the things I've been able to do and it's been a great blessing
(Simon).

Finding purpose in these negative experiences was adopted as a method to construct meaning in these accounts. Promotion of positive experience rendered negative experiences purposeful by making sense of despair:

Following [wife's] breakdown, I became [son's] main caregiver. I had to work, look after him, do the cooking and so on but I didn't mind because it was a great bonding experience
(Simon).

[following separation] I got hit by depression and stayed that way for 7 months. I had to talk to somebody, in desperation I rang my sister. I hadn't had any contact with my family for 25 years and let it all out on an international toll call
(Mark).

I buried 3 daughters and 2 sons in that philosophy [AA] I had to, I couldn't walk between the lampposts if I thought of them and could race on when I put them in the past with the slight hope they would all come back to me one day. Well in many ways they all returned to me when they were ready and I am ever so grateful to be their father again and hear them call me dad
(Simon).

Processes of regaining meaning involved interpreting illness in a positive manner. Methods included learning lessons, finding benefits, and finding purpose. Inherently negative experiences were transformed by adopting these processes. Schwartzberg's (1996) HIV study adopted this position. Garro (1994) argued that illness can be rewarding with the opportunity to increase empathy toward suffering of others. This was evident in the present accounts:

> **Inexplicably cruel when recipient of this information [terminal illness] is young or responsible for dependent children and I acknowledge the agony of unfulfilled tasks when stricken under the age of 60**
> *(Elizabeth).*

In relation to meaning construction, illness became meaningful by interpreting it as an experience which promoted positive change. Schaefer and Coleman's (1992) HIV study highlighted this, engendered by the realisation that time was limited. Illness was exemplified in these accounts as an impetus encouraging moving forward in life:

> **But it [cancer] is brilliant. My body may be affected but my brain is intact and knowing what is happening inside me has got me off my butt and given me the sense of urgency I need to complete all my assignments**
> *(Mark).*

These accounts story integrating negative events into meaningful life narratives. Disruptions imposed by illness and a variety of negative experiences are overcome by regaining meaning. Analysis clearly revealed processes of meaning-making. Specifically, promoting closure in these storied accounts was a prominent narrative feature which revealed meaning.

Finding meaning was established by making sense of illness, changing the life scheme, modifying perceptions of events, and undertaking methods of self-transcendence. Storying a life facing death appears to invariably lend itself to meaning construction. As Singer (1992) noted a meaningful life can and often does result from efforts to overcome difficult impediments.

CONCLUSION

Narrative is fundamental to human experience; stories are the natural way to recount experiences (Sarbin, 1986). Storytelling is an inherent ability which is part of our cognitive repertoire, and does not require teaching (Kemper, 1984). The role of narrative is to organise events and happenings into a coherent framework in which to interpret experience (Baumeister & Newman, 1994; Coffey & Atkinson, 1996; Sandelowski, 1991). The function of narrative is to make sense of experience. Its value lies in its ability to facilitate expression of personal meaning. When we seek to make sense of aspects of our life we use stories to do so (Helfrich et al., 1994). This tendency to utilise narrative to interpret events and experiences is particularly evident when confronted with difficult experiences.

The biographies in this study follow narrative form. These stories are emplotted accounts with a beginning, middle, and end (Polkinghorne, 1995). Central to the plot structure are situations encountered throughout life with methods selected to resolve them (Sarbin, 1986). They present stories about leading meaningful lives, evinced by sources of personal meaning. There is a clear disruption by illness and other interruptions with evidence of loss of meaning. Search for meaning ensues with reconstruction of life story.

The purpose of this study was to examine hospice patient biographies to determine how the process of constructing a biography contributes to meaning formation. Exploring these accounts provided an insight into understanding how these individuals attach meaning to the illness experience. The activity of storying life facing death produced coherent accounts which accepted mortality. The types of stories created emphasised their contextualised construction. This engendered progressive narratives conveying courageous and investigative stories. Given these biographies were constructed to be left behind, it is not surprising they were constructed in this manner. Adoption of these types of stories helped restore meaning as they embraced a positive response toward illness and facilitated making sense of this experience, respectively. Commitment toward realising these goals created order and purpose, important elements for the construction of meaning.

Narrative devices contributed to the construction of coherent stories. Roles assisted by clarifying the narrator's recollection of events and happenings enabling them to make sense of their experience. Epiphany facilitated change in the narrative with the transformation

of illness into an experience of personal growth. Closure encouraged resolution of unfinished business to bring an ending to storied accounts. The importance of resolution has been previously highlighted as a significant factor for meaning construction. Finally, metaphor was a useful device in interpreting difficult experiences encountered in these accounts. This feature engenders clarity, which, combined with comparisons to cultural schemas of illness, enabled the narrator to make sense of their illness. Like epiphany, metaphor promoted reframing the narrator's viewpoint, in which the illness experience became a very personal one. As Kleinman (1988) asserts, narrative devices that structure illness accounts are used for arranging experiences in meaningful ways and for effectively communicating these meanings.

Storying meaning revealed disruptions imposed by illness and other negative experiences were overcome by regaining meaning. Analysis clearly revealed processes of meaning-making in these accounts. Attempts at regaining meaning involved cognitive re-evaluation of views and activities which had previously proffered purpose and meaning. This entailed a cognitive search seeking to make sense of illness (and other disruptions) in order to relate to it personally and integrate it into storied life. Another process of meaning-making concerned modifying life schemes where personal and world views were reframed to accommodate illness experience.

Within this framework goals were modified to ensure actualisation continued to be possible. However, in these stories, the importance was placed upon commitment to goals rather than actualisation per se. The universal goal evinced in these accounts encompassed the resolution of unfinished business. Personal meaning of experience is clarified by affording closure or a sense of completion in the life story (Lashley, 1993). Further, closure is an important component for the promotion of death acceptance (Erikson, 1961). Given death anxiety was a peripheral concern in this study, establishing closure within the storied accounts may have tempered these concerns.

A notable alteration in personal outlooks was the universal acceptance of temporary existence with the adopted perspective of *"living one day at a time."* This invested time with importance and promoted commitment toward goals. Another method of meaning-making involved changing one's perception of negative events, particularly illness. Positive interpretations of events offers less of a challenge to meaning and enables losses to be integrated into the storied life. Finally, methods of self-transcendence were evident in the struggle to regain meaning. With this approach a sense of purpose was attached to suffering, positively transforming illness into a meaningful experience.

This study focused on one type of narrative which involved a special construction. Accounts were produced in a hospice environment by biographers compiling biographies for patients approaching death, which were to be given to significant others. These accounts offer a new way of considering meaning-making. Nevertheless, it is interesting these accounts reveal similar meaning-making processes adopted by other studies examining meaning construction.

Steeves' (1992) BMT study examined tape-recorded interviews. Individuals sought meaning in two ways: renegotiating their social position in a new situations; and through attempts at reaching an understanding of their experiences as a whole. Clearly, the latter approach was identified in the present study. Coward's HIV and cancer studies, adopted phenomenological approaches with written descriptions and interviews. These studies revealed processes of meaning-making through methods of self-transcendence. Again this process was evinced in the current accounts. Finally, O'Connor's (1990) cancer study which examined interview data, exemplified similar processes of meaning-making. Analysis identified seeking understanding of personal significance of diagnosis, reviewing life, changing outlook (restructured and revaluing attitudes toward self, life, and others), and faith.

Regarding findings, several features of this study warrant consideration. Although the number of biographies was small (N=7), the labour intensive nature of narrative inquiry restricts the number of cases studied (Murphy & Kinmonth, 1995). Moreover, this was compensated by the richness of data, making the number of biographies sufficient. Context is another factor which merits attention. The types of stories were influenced by their contextual construction. Presenting these accounts to others naturally effected excluding details, evinced by the frequent comment of *"leaving the bad bits out."* It would have been interesting to examine accounts where "bad bits" were not omitted.

With the biography sample preselected with individual permission and if deceased, family permission, it would have been interesting to examine biographies authored by individuals who did not give copies to others; without this process being contextualised by leaving biographies, they may have adopted different ways of constructing meaning. This possibility is pointed out in Bruner's (1986) three-fold distinction of storied lives: life-as-lived which is what actually happened; life-as-experienced, which are the images, feelings, desires, thoughts, and meanings known to the person; and live-as-told, which is the actual narrative. In accord with this distinction it would be interesting to inspect for variance between life-as-told (storied account) and life-as-experienced (presumably account where copies not given to others).

Contextual construction was not an inherent weakness as analysis was mindful of this effect. Regardless, the presence of an audience is unavoidable with biography construction, therefore the construction will remain, to a degree influenced by its context.

Another contextual influence worthy of future research is the biographer's role in construction. Variables such as level of experience, interviewing styles, and rapport with patients could reveal the extent of this influence and positive and detrimental factors associated with them with regard to meaning construction.

Finally, given death anxiety's peripheral role within these accounts and its demonstrated importance in palliative literature, it would appear beneficial to examine individual's level of death anxiety before constructing their biography and at intermittent intervals during this process. However, given the demands this may impose on patients, this approach would require serious consideration before carrying out.

Clearly, the process of constructing biographies is beneficial for facilitating meaning-making. Given approaching death disrupts an individual's personal narrative and threatens personal meaning, reconstructing this story is vital for re-establishing meaning in life. Lichter and associates (1993) noted that recounting experiences enables individuals to resolve unfinished business, an important element for promoting closure, which engenders meaning. Moreover, they noted the presence of meaning may contribute by positively mitigating death anxiety, improving the quality of life remaining and most importantly, fostering a tranquil death. This study reveals evidence that narrative promotes meaning-making, providing evidence of the value of the Hospice Biography Programme.

By identifying the value of this programme, similar programmes should be encouraged in other hospices. Terminal illness is a prevalent concern for many individuals and their families. The existential process of coming to grips with mortality and meaning in life impacts significantly on one's quality of life and their approach toward death. Specifically, the association between sense of meaning and physical and psychosocial well-being, emphasises its importance for this group. Therefore a programme which can facilitate this, allowing time to be used efficaciously, and promoting a peaceful death, is vital for both individuals and significant others.

However, the value of this approach is not confined to this environment; implications of this study highlight its potential application in many settings. Moreover, given meaning-making is a ubiquitous concern and narrative a natural medium, the value of this approach is extensive. Specifically, this programme would be valuable for those experiencing serious

losses. For example, accident victims, victims of crime, those who have lost significant others and retirement populations. Interestingly, the value of this approach in the latter group is evinced with the recent establishment of a similar venture in a Wellington retirement village. This programme involves trained reminiscent therapists listening to elderly residents talk about their lives (Evening Post, 1997) Although the programme does not involve the formalised mechanics of the Hospice Biography Programme, it incorporates similar principles. Described as "therapeutic conversation" this programme recognises the value of narrative and meaning in populations where meaning is often lost.

In conclusion, storying lives in a coherent framework facilitated construction of meaningful stories. This enabled narrators to assimilate and integrate illness (and other disruptions) into their personal narrative and move toward acceptance of approaching death.

Man is not diminished by suffering, but by suffering without meaning.

(Frankl, 1959)

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