

**A HANDBOOK OF INTERVENTIONS AND SUPPORTIVE COUNSELLING
METHODS FOR FACILITATING A “GOOD” DEATH**

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DEDICATION



This final project is dedicated to Janice Smits (1966 – 1999), who died of cancer at the age of 33. Janice’s legacy lives on in her four children. Janice was the inspiration for my returning to education to become a counsellor. Janice is remembered daily.



This final project is also dedicated to my parents, George Morrice (1923 – 2002), and Audrey Morrice (1928 - 2007), whose spirits left their bodies on the same day, February 4th, five years apart. Death may have taken them physically, but they are alive and well in my heart and mind. Mom and dad are also remembered daily.

ABSTRACT

Over the years, medical science has taken over the art of dying, robbing some individuals and their families of experiencing a good death. This paper is a review of the literature addressing the needs of terminally ill patients and their families. One question I tried to answer is what facilitates “good” pre- and post-death experiences? I found that open communication of personal wishes and relevant information is key. I also found that what constitutes a “good” death varies; physicians tend to focus on the physical components of the illness, whereas patients, their families, and other non-physician caregivers focus on the psychosocial and spiritual aspects of dying. Many writers have observed that defining quality of life is difficult, as it is subjective and changes with time. Some factors that have been identified as working against experiencing a good death are fatigue, the sense of being a burden, and depression. These states are so common and pervasive that some (fully competent) terminally ill patients argue that they should have the right to end their suffering prematurely if they desire. At the same time, spiritual factors may have an important positive impact on existential suffering, quality of life, coping strategies, and the bereavement process. There is no consensus among researchers on the process of grief, exactly how long the grieving period “should” last, or what constitutes “normal” grief versus “complicated” grief. Some have argued that the lack of standardized definitions is highly problematic in that it may lead some clinicians to misdiagnose patients and prescribe unnecessary medications. It appears that it is impossible to apply a “one size fits all” approach to the grief process, due to varying individual, social, and cultural factors. The therapy approaches presented in this paper help to enhance quality of life, manage anxiety, reclaim some control, and facilitate the bereavement process.

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CHAPTER I

Introduction

Death is inevitable. We can't escape it or elude it - we can only postpone it. Over the years, medical science has taken over the art of dying. Some dying individuals and their families have been robbed of experiencing a good death (Parker, 2004). We do not have to “approach serious illness and death with terror, dread, and grief at leaving all we love” (Weenolsen, 1996, p. 254). Rather, with the help of palliative care and a strong support system, death can be a carefully planned experience.

The voices of the dying and their families are now being heard and are being used to change the experience from being an isolating medical event to one that is subjective, unique, and intimate. Palliative care is intended for the benefit of not only the dying but all members of the family unit. It cannot be stressed enough how a palliative approach can make a positive difference in the experience of death and dying. It offers the opportunity for a “gentle” death versus one in which suffering is so unbearable, for both the dying individual and those who are witnessing it, that assisted suicide is considered as an alternative (Wilson et al., 2007). Each person experiences death (their own or that of a loved one) differently, and there is no one-size-fits-all approach to counselling or therapy. Hirai, Morita, and Kashiwagi (2003) argued that each person affected by the dying process (the dying individual himself or herself, family members, and friends) suffers in a unique way and should be individually assessed, then offered specific treatment methods geared to their needs and preferences.

The purpose of this literature review is to summarize the wants and needs of terminally ill patients and their families, which are associated with “good” pre- and

post-death experiences. The following questions guided this review: (a) What is a good death? (b) How can dying individuals achieve a good death? and (c) How can the experience of loved ones be enhanced?

The overall purpose of this paper is to present a compilation of theoretically driven interventions, strategies, and resources that might eventually become a handbook for the dying, their family members, caregivers, and other professionals. The experience of dying does not have to be filled exclusively with anxiety and sadness. With strategic counselling, support, and careful planning, death can be experienced and appreciated as a natural process of life.

Personal View

I have a personal interest in seeing this project to completion due to my own experience of helping take care of my elderly, ailing mother, who suffered from a myriad of chronic diseases that led to her death on February 4, 2007. I experienced the negative impact of my mother's perception of being a burden to others, her loss of dignity, and the despair that resulted from her loss of autonomy and choices. After my mother's death, I experienced a roller-coaster ride of grief and distress. I am convinced that a handbook about this experience and the available resources would have been beneficial to me, both pre- and post-death. Pre-death, the handbook could have helped me to identify and understand the negative effects of self-perceived burden and loss of dignity and provided me with strategies to enhance my mother's quality of life. Post-death, such a handbook would have been helpful for understanding how grief manifests itself and progresses and provided some insight into normal grief reactions.

CHAPTER 2

What Do Dying Patients Desire or Need?

Death is a universal occurrence, but for those who are terminally ill, it takes on a new and urgent meaning. For these individuals, death has become an imminent reality that demands thought and preparation. It has been argued that medical science has taken over the “art” of dying and that this *medicalization* of death often precludes terminally ill individuals and their families from achieving what they consider to be a *good death* (Parker, 2004).

What most dying individuals desire is pain and symptom control, achieving a sense of spiritual well-being and peace, preparing and strengthening relationships with loved ones (Breitbart, Gibson, Poppito, & Berg, 2004; Weenolsen, 1996), to be able to die at home (Kristjanson & Aoun, 2004), and to avoid a prolonged deathbed vigil by their loved ones (Callanan & Kelley, 1992). Steinhäuser and colleagues (2000a) conducted a cross-sectional, random national survey of seriously ill patients (n = 340), recently-bereaved family members (n = 332), physicians (n = 361), and other care providers, such as chaplains, nurses, social workers, and hospice volunteers (n = 429). From this, they identified 26 factors that participants considered to be important at the end of life which included (a) being kept clean (99%), (b) appointing a proxy decision-maker (98%), (c) having a nurse with whom one feels comfortable (97%), (d) knowing what to expect about one’s physical condition (96%), (e) having someone who will listen (95%), and (f) maintaining one’s dignity (95%). See Appendix A for the complete list of factors.¹

Other researchers have reported what most dying patients do *not* want. For example, most fear losing their dignity, being dependent or a burden, feeling out of

control (Emanuel & Emanuel, 1998; Weenolsen, 1996), not forgiving or reconciling with others, or not being forgiven by God or a higher power (Breitbart et al., 2004).

A “Good” Death

There is an increasing focus in the literature on the conditions that characterize a good death. For example, McNamara, Waddell, and Colvin (1995) defined death “as ‘good’ if there is an awareness, acceptance and preparation for death by all...interactants who may include family, friends and health professionals” (p. 223). Emanuel and Emanuel (1998) deemed a good death as one in which a dying individual and his or her family experiences the end of life without unnecessary stress, anxiety, pain, guilt, or suffering. Shneidman (2007) stated, “[t]here is no single best kind of death” (p. 245), and likened a good death to a well-fitting glove, meaning that if it fits, it’s appropriate for that person. According to Shneidman’s review of the literature, there are 10 criteria for a good death: natural, mature, expected, honorable, prepared, accepted, civilized, generative, rueful, and peaceable. He suggested a “golden rule” for the dying individual to keep in mind: “Do unto others *as little as possible*” (p. 246). The intentions behind Shneidman’s list and golden rule are for the dying to be able experience a death with grace and dignity, and to ensure that the survivors experience as little pain as possible after the death. Thus, Shneidman argued that those dying individuals who strive to obtain the components of a good death and follow the golden rule will die a “courtly death,” and the way they died will be remembered as among the best things they ever did by the loved ones left behind.

Over a four-month period, Steinhauser and colleagues (2000b) convened 12 focus groups to gather descriptions of a good death from patients, families, physicians, and other care providers (e.g., nurses, chaplains, social workers, and hospice volunteers).

Seventy-five participants, aged 26 to 77 years, were recruited from a university medical center, a Veterans Affairs medical center, and a community hospice. They were placed into focus groups according to their role and asked to discuss their personal experiences with death and to reflect on what made those deaths good or bad. After analyzing the transcripts, the researchers conducted in-depth interviews with each individual. Both the focus group discussions and in-depth interviews were audiotaped and transcribed. Six major components emerged from the discussions that characterized a “good” death: (a) pain and symptom management; (b) clear decision-making; (c) preparation for death; (d) completion (e.g., a life review); (e) contributing to the well-being of others (e.g., gifts, time, knowledge); and (f) affirmation of the whole person. Of particular interest was the finding that physicians’ ideas of what constitutes a good death differed from those of other participants. “Physicians offered the most biomedical perspective, and patients, families, and other health care professionals defined a broad range of attributes integral to the quality of dying” (p. 825).

In a national survey, Steinhauser and colleagues (2000a) randomly selected 1462 participants (340 patients, 332 bereaved family members, 361 physicians and 429 other care providers) from the national Veterans’ Affairs database. They were asked to rate the importance (i.e., “1” being most important and “9” being least important) of 44 attributes that are typically considered to be important at the end of life. Survey items were generated from Steinhauser and colleagues’ (2000b) previous focus group interviews (discussed above). The objective of this study was to obtain further empirical evidence of what patients, families, and health care professionals view as important factors at the end of life. The researchers identified 26 items rated as being important by more than 70% of

participants. The data revealed areas of strong agreement as well as variation in responding. Eight specific attributes were rated as “very important” by patients but not physicians. They were: (a) mental awareness (patients 92%, physicians 65%), (b) being at peace with God (patients 89%, physicians 65%), (c) not being a burden to family (patients 89%, physicians 58%), (d) helping others (patients 88%, physicians 44%), (e) spirituality/religion (patients 85%, physicians 55%), (f) having funeral arrangements completed (patients 82%, physicians 58%), (g) not being a burden to society (patients 81%, physicians 44%), and (h) feeling that one’s life is complete (patients 80%, physicians 68%). According to the authors, this study “highlight[ed] one of the challenges of comprehensive end-of-life care: attending to aspects of care that are not intuitively important to clinicians but are critical to patients and their families” (p. 2481).

Smith (2000) stated that the “[d]ebate over whether people are dying badly or well obviously depends on a definition of a good death” (p. 129). As Steinhäuser and colleagues (2000a) pointed out, there is no one definition of a good death; quality end-of-life care is a process that is negotiated and renegotiated among patients, families, and health care professionals as the disease progresses. Smith (2000) concluded from his review of the literature that the concept of dying well is based on three basic themes: autonomy, control, and independence. The authors of the report, *The Future of Health and Care of Older People: The Best is Yet to Come* (Debate of the Age Health and Care Study Group, 1999, as cited in Smith, 2000), identified 12 principles of a good death, with which, Smith argued, all those in the helping professions should become familiar. These principles included: (a) knowing when death is coming and what can be expected; (b) having control over symptoms, pain relief, aspects of timing (e.g., having time to say

goodbye, being able to leave when the time is right, not having life prolonged pointlessly), knowing where the death will likely occur, and who will be present; (c) having access to information and expertise of whatever kind is needed, spiritual and emotional support, and hospice care in any location; (d) making advance directives and being sure they will be followed; and (e) being afforded dignity and privacy. Thus, achieving a good death is more than simply being pain-free.

However, the idea of what constitutes a ‘good’ death will vary depending on one’s perspective (e.g., patient, family members, physicians, researchers). For example, from a medical perspective, fighting the disease, pain and symptom management, and pharmacological and physiological concerns are the main elements of facilitating a good death. In contrast, the main concerns from a palliative care perspective are psychological, psychosocial, emotional, and spiritual factors (e.g., attending to the wishes of the patient).

On the basis of their research, Steinhauser and colleagues (2000a, 2000b) argued that physicians should take the values and preferences of patients and their families into consideration and converse with them about end-of-life decision-making. This may help improve the care and quality of life for those at the end of life and may also benefit the caregivers as well. It seems reasonable that this process requires clear communication of personal wishes and relevant information between patients and those involved in their care.

Quality of Life

When medical science can no longer halt the progression of disease, palliative medicine takes over and the focus of care turns to quality of life (QOL), or as Steinhauser, Clipp, and Tulsky (2002) suggested, the “quality of dying” (p. 408). The

main focus of palliative care is to improve QOL for those who are dying (Kübler-Ross, 1981; Lo et al., 2001).

Lo and colleagues (2001) argued that QOL is influenced by environmental, cultural, and social factors, and is therefore subjective, flexible with time (Byock & Merriman, 1998), and difficult to define and measure. Kuhl (2002) echoed this assertion and further stated that “[o]nly you can define or describe what ‘quality of life’ means to you. Your definition might be very different, not only from those in the room but also...[from your own perspective] in the not-too-distant past” (p. 129). McPeak (2003) defined QOL as the patient's ability to enjoy normal life activities, as well as the amount of happiness and contentment one enjoys in life, not just in the material sense, but also in the sense of spiritual and mental well-being.

The McGill Quality of Life (MQOL) questionnaire (Cohen, Mount, & Strobel, 1995) is a multidimensional, 16-item measure based on data from patient interviews and other, similar instruments. Developed in Canada, it was designed to measure patients’ subjective sense of QOL in four domains: physical, psychological, existential, and support. On the basis of their research, Lo and colleagues (2001) concluded that the MQOL has high cross-cultural validity with respect to Hong Kong Chinese. They argued that for patients with advanced incurable illnesses, “existential well-being is more than just a Western concept, and that its influence on QOL is present in Hong Kong Chinese” (p. 394). While QOL may be subjective and difficult to define, Lo and colleagues found that there are many cross-cultural similarities in terms of QOL concerns and desires. For example, both Western and Eastern samples reported that it is important to be treated

with dignity or respect, not only by family members, but also by health care staff, and to maintain physical touch with others (Lo et al., 2001; Steinhauser et al., 2000a, 2000b).

Byock and Merriman (1998) argued that it is imperative to openly discuss with patients their view of quality-of-life, and then respond to their needs with appropriate interventions and resources. To the extent that the terminally ill have what they consider to be QOL, they are more likely to experience a “good” death.

Communication of End-Of-Life Desires

Unwanted, death-prolonging treatments are frequently provided for patients who have not informed others of their treatment wishes prior to their illness. Dying and death are difficult topics to discuss, but it is important that the terminally ill feel free to convey their wishes openly. Early communication about goals and preferences can improve patient care at or near the end of life by enhancing choice and providing critical information to caregivers and healthcare providers. The following are just two ways in which this may be accomplished.

Go Wish game. The Coda Alliance developed the *Go Wish* game to stimulate discussion of values, wishes, and priorities for the end of life, between patients and their caregivers (*Go-Wish*, n.d.). The *Go Wish* game consists of 36 cards, each of which depicts a statement inspired by Steinhauser and colleagues’ (2000a, 2000b) research on what the very sick and dying indicate is important for them at the end of life (e.g., to die at home and to be free from pain). The *Go Wish* game can be played solitaire, in pairs, or in groups, using two or more decks of the cards provided. The cards can be read privately or aloud to those who have poor eyesight, literacy challenges, limited understanding of the English language, or mild dementia. The gist of the game is to determine what is

important to individuals at the end of life, express one's values and wishes for the end of life, and to reflect on how this information may be communicated to others. The *Go-Wish* game can also be played online via the Internet.

The *Go Wish* game has been tested and used by family members, health educators, hospice workers, nurses, physicians, and social workers, in a variety of settings, including church meetings, community meetings, family gatherings, health education classes, medical conferences, and synagogue meetings. The game allows individuals to start conversation in a fun, light way about serious, troubling issues that most find difficult to discuss.

Advance directives. Molloy (2005) described an advance directive (AD) as a legally binding document, which contains clear, written statements about an individual's wishes regarding healthcare and medical treatments at the end of life. The AD can be used to "speak" on one's behalf should one become incompetent and unable to make one's wishes known to family and medical personnel. An AD that deals specifically with healthcare is called a *living will* or *healthcare directive*. In Canada, there are two types of healthcare directives, instructional and proxy.

An instructional healthcare directive stipulates which treatments are wanted or not wanted - and there is much to consider. For example, Molloy (2005) described four ways in which a person can be nourished (basic feeding, supplemental feeding, intravenous, and tube feeding). There are also four levels of care that one can receive from healthcare providers: (a) intensive care, which includes all care possible; (b) surgical care, which involves only diagnostic surgery, dialysis, and ventilation; (c) limited care, which comprises antibiotics, x-rays and oxygen, but no emergency surgery, dialysis, or life

support; and (d) palliative care, the least intrusive, which may be limited to keeping the patient warm and dry, and as pain-free as possible.

A proxy directive appoints substitutes for decision-making on behalf of an individual should he or she become unable to do so. Molloy (2005) cautioned that more than one person should be nominated for this task, to be sure that a substitute will be available to convey the individual's healthcare wishes. As well, a wallet-sized copy of the AD should be kept in the individual's purse or wallet, to inform healthcare professionals of whom to contact for consultation.

Communicating clearly what one does and does not want to happen, should one become incapacitated and unable to communicate, takes everyone else "off the hook" for making difficult decisions on one's behalf (Molloy, 2005). Russ and Kufman (2005) emphasized that family members have to live with the decisions made under pressure and in emotionally fraught states. This not only puts an added burden on the situation, but it can also cause significant distress for family members long after the crisis is over. Moreover, Molloy (2005) argued that doctors too do not want the responsibility for "guessing" the patients' treatment wishes.

Right to Choose a Hastened Death

"Not everybody is content to let death come in its own time. Some people want death to come sooner, while others want to delay it as long as possible" (Kerr & Kurtz, 1999, p. 119). Wanting to die prematurely from terminal illness does not necessarily indicate that one is suffering from clinical depression or some other psychological disorder. Existential factors, such as feelings of hopelessness, perceiving oneself as a burden to others, and undermined dignity, are frequently experienced by those with

terminal illness, may occur independently of depressive symptoms, and have been associated with the desire for a hastened death in many studies (e.g., Breitbart et al., 2000; Chochinov, Wilson, Enns, & Lander, 1998; McClain, Rosenfeld, & Breitbart, 2003; Morita, Sakagushi, Tsuneto, & Shima, 2004; Sullivan, Hedberg, & Flemming, 2000; Wilson, Curran, & McPherson, 2005; Wilson et al., 2007). Pain is also an important consideration for terminally ill patients who wish to end their suffering (Hudson et al., 2006).

From a philosophical perspective, terminally ill patients who are competent, in constant, debilitating pain, and have no chance of recovery, have argued that they should have the right to decide when they have “had enough” of conventional medicine, and be allowed to end their suffering prematurely if they so desire (Wilson et al., 2007). This choice may be empowering to individuals who have been robbed of their autonomy by terminal illness, and it may help alleviate some of the anxiety associated with the possibility of a prolonged deathbed vigil. Some terminally ill patients worry about their families’ well-being as they watch the patient, their loved one, slowly and painfully slip away. “Pain cannot be ignored....It is difficult to sit in the presence of a person with uncontrolled pain. At times the anguish is unbearable” (Kuhl, 2002, p. 93).

Wilson and colleagues (2007) conducted the Canadian National Palliative Care Survey, which targeted patients across Canada receiving palliative care for cancer. The survey measured participants’ attitudes toward the legalization of euthanasia or physician-assisted suicide (PAS). Wilson and colleagues were interested in whether there were identifiable differences between those who support the legalization of hastened death and those who do not.

Out of the 379 patients interviewed, 238 (62.8%) believed that euthanasia or PAS should be legalized, of which 51 (39.8%) reported that they would consider this option in the future if it were, and 22 (5.8%) indicated that they would exercise this right immediately if they could. Wilson and colleagues (2007) found that those who supported legalization provided many reasons for doing so, including autonomy, compassion, concern for others, and perceived futility. Those against legalization (141 or 37%) cited reasons such as moral opposition, it would be giving the physician too powerful a role, and religious concerns. Wilson and colleagues concluded that relative to those opposed to PAS, those who would consider a legalized, hastened death had (a) weaker religious beliefs, (b) fewer moral objections to euthanasia or PAS, (c) more complex symptoms, (d) less ability to perform daily activities, (e) a greater number of symptoms self-rated as distressful, and (f) a lower likelihood of being on antidepressant medications.

Thus, Wilson and colleagues (2007) found that both physical and psychological symptoms are important considerations in why individuals might consider a hastened death. The main physical concern is pain. For example, nine participants who desired a hastened death indicated pain as the main reason. Consistent with this finding, two participants changed their minds about wanting a hastened death during the course of the study after they received adequate alleviation of their pain symptoms.

Spiritual Well-Being

Another desire commonly communicated by dying patients is the need for spiritual well-being, which is not necessarily related to any organized religion (Wilson et al., 2007). Increasingly, clinicians and researchers are recognizing the importance of spiritual factors and the impact that spiritual well-being may have on the quality of life

for dying individuals (Bourgeois & Johnson, 2004; Breitbart et al., 2004; Emanuel & Emanuel, 1998; Klass, 1996; Lo et al., 2001; McClain, Rosenfeld & Breitbart, 2003; Moadel et al., 1999). However, it is most important that the pain is under control before psychosocial and spiritual counselling can be maximized (Lidstone et al., 2003). A person-centered approach to patient care “underscores the significance of spirituality and meaning-making as important resources for coping with emotional and existential suffering as one nears death” (Breitbart et al., 2004, p. 366). Spiritual well-being may protect patients against end-of-life despair addressed below (Breitbart et al., 2004; McClain et al., 2003), and facilitate preparation for the impending death (Bourgeois & Johnson, 2004). The maintenance or development of spiritual well-being has been found to be a crucial aspect of coping and adjustment to the end-of-life experience (Donnelly et al., 2000). Therefore, it is imperative that spiritual and existential needs are assessed for every patient facing life-threatening illness (Byock & Merriman, 1998; Lo et al., 2001; Moadel et al., 1999). Having a belief that life transcends death may increase the coping abilities of the dying individual and his or her family members.

Dr. Wayne Dyer (2004) emphasized the importance of having a strong spiritual belief in life continuing in some form after death, such as that each of us is an eternal soul in a temporary physical form. This way of thinking provides comfort for some people and may lessen their fear of death. One study found that people with little or no religious or spiritual beliefs tended to resolve their grief more slowly than those with strong beliefs (Walsh, King, Jones, Tookman, & Blizard, 2002). Some writers have argued that spiritual and religious beliefs may aid in coping with impending death by providing explanations

for sickness and suffering and by giving one a sense of meaning and hope (e.g., Chochinov & Cann, 2005; Stephenson, Draucker, & Martsolf, 2003).

Inherent in the belief that we are spiritual beings simply having a “human experience” is the hope that once the human aspect is gone, the spiritual one lives on, thereby transcending death. This notion may benefit the bereaved, in that they hope to join loved ones who have gone before them; the loneliness may be easier to bear. A strong spiritual belief system also may help calm common fears in dying patients, such as fear of the unknown and what lies ahead, and concern over leaving loved ones to cope alone, by providing answers and instilling peace of mind (Jenkins & Pargament, 1995). Research has shown that patients’ spiritual and/or religious needs may vary according to age, cultural background, gender, ethnicity, marital status, and education (Astrow, Wexler, Texeria, He, & Sulmasy, 2007; Taleghani, Parsa, & Nasrabadi, 2006). Thus, any form of psychosocial support should be adapted to meet the needs of individual patients.

CHAPTER 3

Factors That Work Against Experiencing a “Good” Death

This section will describe the nature and effects of fatigue and burden, and some psychological states associated with terminal illness, including depression, end-of-life despair, and demoralization syndrome.

Fatigue

Fatigue is an important consideration for both patients and caregivers, due to its potential to impact their QOL and ability to look after themselves and others (Jensen & Given, 1991; Rhodes, Watson, & Hanson, 1988; Stone et al., 2003). Some researchers have acknowledged that fatigue is difficult to define or even describe (e.g., Krishnasamy, 2000; Piper et al., 1998; Ream & Richardson, 1996, 1997). In their review of research into cancer-related fatigue, Ream and Richardson (1996) found that fatigue is defined and operationalised differently according to professional roles. For example, psychiatrists tended to consider fatigue as mood-related, whereas most physicians related fatigue to poor physical condition. Ream and Richardson compiled the characteristics of fatigue that were identified in numerous studies to provide a comprehensive definition: “Fatigue is a subjective, unpleasant symptom which incorporates total body feelings ranging from tiredness to exhaustion, creating an unrelenting overall condition which interferes with individuals’ ability to function to their normal capacity” (p. 527).

Ream and Richardson (1997) also reported that cancer-related fatigue is different from “everyday” or acute fatigue, which is a temporary state that follows lack of sleep, or mental or physical exertion, and which subsides with rest. In the cancer-related (or chronic) condition, individuals become fatigued from even modest effort and rest does

not bring sufficient relief. Cancer-related fatigue has common features that can impact patients emotionally (e.g., irritability), behaviourally (e.g., appearance), cognitively (e.g., concentration) (Piper et al., 1998), and spiritually (e.g., loss of hope) (Jensen & Given, 1991; Potter, 2004). Potter (2004) reported that many cancer patients claim that fatigue negatively impacts them in a global sense, and they complain that because fatigue is not perceived as a life-threatening symptom, its impact tends to be minimized by family members and health-care providers.

Walsh, Donnelly, and Rybicki's (2000) consultations with 1000 cancer patients in a Palliative Medicine Program revealed that fatigue is one of the most frequently reported symptoms in those in advanced stages of the illness. However, as Coackley and colleagues (2002) concluded, fatigue is the most untreated symptom of cancer. Nail (2002) explained that although research on fatigue has grown significantly in the last century, little is known about the mechanisms that underlie it, due to a lack of consensus as to what fatigue is. Most researchers seem to assume that fatigue is a side effect of cancer treatment, even though oncologists often see fatigue as a symptom of cancer, exacerbated by the treatment (Nail, 2002; Ream & Richardson, 1997). More research is necessary to understand how fatigue is manifested and how to manage it.

Nail (2002) described various pharmacologic and nonpharmacologic treatments that have been evaluated for alleviation of fatigue in cancer patients. Pharmacologic interventions include (a) erythropoietin, for correcting chemotherapy-induced anemia; (b) psychostimulants, such as methylphenidols, for bolstering energy and reducing fatigue; and (c) antidepressants, because it is widely accepted that fatigue is also a symptom of depression. Nail emphasized that some cancer patients experiencing fatigue may not in

fact be depressed and therefore, antidepressants may not be suitable for or helpful to them.

Current nonpharmacologic interventions for fatigue are (a) exercise, (b) energy conservation, (c) sleep and rest, (d) stress management and psychosocial support, (e) nutrition and nutritional supplements, and (f) restorative activities such as concentration exercises (Nail, 2002). Stone and colleagues (2003) observed that recent studies have found that exercise is more effective than rest for reducing fatigue. Nail (2002) noted that despite the popularity of nutritional supplements, there are no published studies of the effects of nutritional supplements on cancer-related fatigue.

Fatigue that accompanies advanced illness can not only change the patient's routine, but can also change the family dynamic (Jensen & Given, 1991). Fatigue can rob patients of their autonomy and independence, and this situation may lead to family and friends performing duties for which the patient was previously responsible. For example, older children may be assigned the care of younger siblings, fathers may have to grocery-shop and cook meals, and friends may be called upon to help with carpooling to school, sporting activities and the like (Jensen & Given, 1991).

Some studies have found that higher levels of patient fatigue are related to higher levels of fatigue in the caregiver (e.g., Jensen & Given, 1991). Stone and colleagues (2003) conducted a cross-sectional survey of cancer patients ($n = 576$), caregivers ($n = 454$), and healthcare providers ($n = 368$). Their responses revealed that one in five caregivers had taken three or more days off work in the previous month due to the needs of the patient. According to Jensen and Given (1991), this may impact the caregivers physically, psychologically, and financially. For example, caregivers who have to stay at

home more often to care for the patient's escalating needs might worry about job security because they are taking too much leave from their job, or worry about how they are going to pay bills with reduced pay. These increasing stressors may eventually contribute to "caregiver burnout," which could further interfere with employment. Other studies of fatigue in caregivers indicate that their needs are not being properly recognized by either the caregivers themselves or medical professionals, and thus are going untreated (Keegan et al., 2001; Kristjanson & Aoun, 2004; Larson, 1993; Lynn, Lynch Schuster, & Kabcenell, 2000). This may be one reason for how and why caregivers can become patients themselves (Larson, 1993; Lynn et al., 2000).

Burden

Perceptions of carrying a burden (in caregivers) or being a burden to others (in patients) can be understood from the social psychological perspective (McPherson, Wilson, & Murray, 2007). According to Adams' (1963) version of equity theory, relationships are assessed through a balance of contributions (giving help and support) and benefits (receiving help and support) between individuals. When individuals perceive they are giving more than they are receiving in the relationship, or vice versa, this perceived inequity may cause them to feel uncomfortable with the imbalance. Distress will be experienced until psychological equity is restored. Individuals are motivated to restore equity by altering their own contributions (giving and receiving) to the relationship or by altering their perception(s) of the situation.

In the case of terminal illness, opportunities for reciprocity in the relationship may be compromised. As the disease progresses, caregivers become more and more responsible for helping the patient and over time, may begin to perceive the patient as a

burden. In turn, the patient may become depressed under the stress of losing his or her independence and worry about being a burden to the caregiver. This is what Wilson and colleagues (2005) referred to as the patient's "self-perceived burden" (SPB).

Much has been written about caregiver burden, but little has been published on the care recipient's experience of feeling like a burden (Wilson et al., 2005). Only recently has SPB become a focus of research (Morita et al., 2004; Sullivan et al., 2000; Wilson et al., 2005). Cousinau, McDowell, Hotz, and Hebert (2003, as cited in Wilson et al., 2005) defined SPB as "a multidimensional construct arising from the care-recipient's feelings of dependence and the resulting frustration and worry, which then lead to negative feelings of guilt at being responsible for the caregiver's hardship" (p. 111).

SPB may influence (a) how one makes important decisions regarding treatment (Ashby et al., 2005; Cohen-Mansfield, Droge, & Billig, 1992), (b) how one writes an advance directive (Singer et al., 1998), and (c) where one will receive care until the end of life (e.g., choosing a hospice setting rather than burden caregivers with care at home) (Thomas, Morris & Clark, 2004). SPB has also been correlated with thoughts of a hastened death (Morita et al., 2004).

Psychological States Associated With Terminal Illness

Individuals with terminal cancer face many physical and psychological challenges as their physical life is coming to an end (Kübler-Ross, 1981). Physical distress may be manifested in symptoms such as fatigue, drowsiness, insomnia, dyspnoea (shortness of breath), anorexia, vomiting, nausea, and pain. As well, "[s]evere, unrelieved pain takes a terrible toll on the patient's physical and emotional well-being, compromises his or her quality of life, and can become very stressful for the family and loved ones" (Lynn et al.,

2000, p. 43). Psychological distress may appear as symptoms such as sadness, anxiety, irritation, frustration, anger, fear, depression, and confusion (Emanuel & Emanuel, 1998). These symptoms may contribute to the development of psychological disorders such as those described below (Ryan et al., 2005).

Depression

Psychological distress may reveal its presence in the form of depression. Clinical depression is manifested by a combination of symptoms that interferes significantly with normal daily activities. The diagnostic criteria for Major Depressive Disorder (MDD) in the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 1994) include a persistent depressed mood (e.g., feeling sad, anxious, empty, low), along with four other related symptoms, for a period of at least two weeks. Rates of depression in palliative patients vary across studies, ranging from 3.7 to 58% (Kelly, McClement, & Chochinov, 2006). Kelly and colleagues (2006) speculated that the variability in rates of depression across studies might be due to (a) different definitions of depression; (b) different population samples; (c) physical symptoms that mimic symptoms of depression (e.g., fatigue, loss of appetite, and weight); and (d) different assessment methods. Pereira and Bruera (2001) argued that depression is under-diagnosed and undertreated in the palliative cancer population, and they attributed this to professionals' common assumption that depressive symptoms are side-effects of cancer treatments (e.g., chemotherapy) or due to the physiological effects of the advancing illness itself.

End-of-life despair. One form of depression found in some terminally ill patients has been called "end-of-life despair" (McClain et al., 2003). End-of-life despair differs

from MDD in that it is related more to feelings of hopelessness and loss of meaning in life than to feelings of sadness per se. Patients who are diagnosed with MDD may or may not experience hopelessness or loss of meaning as prominent symptoms of what appears to be depression; therefore, some patients may rate highly on the *Beck Hopelessness Scale* (BHS; Beck, Weissman, Lester, & Trexler, 1974) but may not meet criteria for a diagnosis of clinical depression (Breitbart & Heller, 2002). End-of-life despair refers to a triad of feelings of hopelessness, the desire for a hastened death, and thoughts of suicide (McClain et al., 2003). Feelings of hopelessness can lead some to thoughts of wanting to end their suffering prematurely. While there are drug therapies to treat the various symptoms of MDD, Breitbart and Heller (2002) report that there are no known drug therapies to treat the symptoms of end-of-life despair.

McClain and colleagues (2003) conducted an 18-month study of 160 terminally ill cancer patients whose life expectancy was less than three months. They were testing the hypothesis that spiritual well-being has an impact on coping with end-of-life despair as patients enter the terminal phase of illness. The investigators interviewed patients at their bedside using several self-report measures and standardized tests (i.e., *Functional Assessment of Chronic Illness Therapy – Spiritual Well-being Scale* (Brady, Peterman, Fitchett, Mo, & Cella, 1999), *Hamilton Depression Rating Scale* (Hamilton, 1960), BHS (Beck et al., 1974), *Schedule of Attitudes Towards Hastened Death* (Breitbart et al., 2000)). Multiple regression analyses showed that the ability to find or maintain meaning in one's life during the terminal phase of illness and spiritual well-being were negative correlates of end-of-life despair. For example, those who scored higher on measures of hopelessness were reportedly less spiritual or religiously affiliated. McClain and

colleagues (2003) concluded that the patients' sense of meaning in their life and their spiritual well-being may provide some protection against end-of-life despair. In addition, providing support that enhances spiritual well-being helps to keep psychological distress to a minimum.

Demoralization Syndrome (DS)

“The core phenomena...[of DS] are hopelessness, helplessness, powerlessness to cope and to change things (impotence or incompetence), the loss of a sense of control and security and meaninglessness; in short, existential despair” (ED) (Parker, 2004, p. 765). Parker further described ED as the raw fear that most of us feel when thinking about our mortality and aloneness in the world and what may become of us in death.

Parker's (2004) literature review of DS revealed that while many of the symptoms of DS are similar to those of depression, there are several critical differences. For example, loss of motivation and social isolation can be present in both depressed patients and those suffering with DS. However, whereas the defining characteristic of major depression in adults is depressed mood or loss of interest in major activities, the defining feature of DS is existential despair (ED). As well, depression prevents patients from experiencing pleasure in the present moment, whereas demoralized patients can experience pleasure in the present, but are deprived of anticipatory pleasure (Kissane, Clarke, & Street, 2001, as cited in Parker, 2004). A further distinction is that demoralization appears to be the common denominator in individuals (including those who are depressed, personality-disordered or cancer stricken) who consider ending their life prematurely (Clarke & Kissane, 2002, as cited in Parker, 2004).

Kissane and Kelly (2001) also identified several dimensions of DS that distinguish it from major depression, including disheartenment, a loss of meaning, and a sense of failure. From there, Kissane and colleagues (2004) developed a Demoralization Scale and validated it in a study of 100 patients with terminal cancer. They concluded that their self-report scale does reliably differentiate DS from depression, and suggested that it might also be useful for measuring change in DS symptoms.

Although DS is often confused with major depression, many researchers consider DS to be a distinct psychiatric disorder (e.g., Kissane, 2004; Kissane & Kelly, 2001; Parker, 2004). Parker (2004) warned that demoralized symptoms should not be considered as “normal” responses in the terminal phase of serious illness, and if left untreated, may lead some individuals to desire a hastened death.

CHAPTER 4

Psychological Interventions and Strategies That Support Quality of Life

In general, the following interventions are designed to help individuals “normalize” the ensuing death event and assist in promoting some sense of personal control. They can all be used in conjunction with other therapies.

Understanding the Psychosocial Phases of Terminal Illness

The saying, “knowledge is power,” may be of particular importance to those facing death. Having knowledge about the psychosocial phases of terminal illness, as well as about the physical course of a specific terminal illness, may help patients understand what might happen to them as the disease progresses. It also may help them to understand that what they are thinking and feeling is normal, and to know that help is available.

From his review of the literature, Bustamante (2001) concluded that there are four psychosocial phases that individuals go through: (a) diagnosis, (b) alleviation and mitigation, (c) general decline and deterioration, and (d) dying and death. The initial diagnosis may evoke an existential dilemma around the question, “How long do I have to live?” Anxiety, anger, vulnerability, and fear may overtake the individual for a period, until homeostasis is re-established. Some estimate this period can last up to 100 days from the initial diagnosis, with the length depending on the patient’s personality, evidence of the illness, and hope for a cure (Bustamante, 2001).

The second stage (alleviation and mitigation) will also vary in duration, depending on the specific illness. In this stage, patients hope to stave off the illness or try to prevent a relapse by incorporating wellness techniques into their lives, such as special

diets, holistic alternatives, and exercise. Bustamante (2001) suggested that the more aggressive and present the illness is in this second stage, the more likely it is that the patient will experience psychological pain.

In the third phase (decline and deterioration), the patient may experience weight loss and fatigue, as well as the increasing sense that all previous attempts to stave off the illness have been futile. They may struggle with feelings of loss of control, vulnerability, and desperation. Patients often choose to deny or displace their illness as a way of coping with their situation. Bustamante (2001) asked “[w]hen the person is in this phase, we encounter one of the most controversial dilemmas of therapeutic strategy. How long should modern medical treatment be continued? What high-tech diagnostic procedures should we continue to accept?” (p. 51). This is a difficult period, in which hopes can be shattered by the admission (by either the patient or physician) that the disease is not only present, but taking over.

As physical deterioration advances, the patient moves into the fourth and final phase, dying and death. Individuals close to dying tend to sleep more, are more focused on their internal processes, and they may make up a mental “balance sheet,” reviewing the value of their life as it was lived. The results of this analysis may produce satisfaction or it may cause psychological anguish. In this stage, therapy can help dying individuals create a new sense of hope.

This hope takes the form of a desire not to suffer pain in dying, to hear that the closest relatives have accepted their inexorable departure, to see and say goodbye to the most important persons in their life, [and] to finally attain rest and a better life beyond death. (Bustamante, 2001, p. 51)

Psychosocial Interventions

The impact of cancer on patients' emotional, physical, and social functioning can be far-reaching, often creating challenges for the individual's family, community, and spirituality. Psychosocial oncology, which is a "whole-person" approach to cancer concerned with understanding and providing treatment for a wide range of cancer patients' issues, was developed to address these needs (*Canadian Association of Psychosocial Oncology*, n.d.). Psychosocial oncology includes interventions such as counselling, support groups, expressive therapies (e.g., art, music, play therapies) and mindfulness meditation (BC Cancer Agency, 2007).

Hira and colleagues (2003) conducted a questionnaire survey of 456 Japanese healthcare professions (146 psychiatrists, 42 psychologists and 268 palliative care nurses), in which they were asked to rate the effectiveness of 25 clinical psychosocial interventions for the existential suffering of terminally-ill cancer patients. The specific interventions were chosen after a review of the literature indicated that specialists recommended them most often for treatment of existential despair. The questionnaire consisted of three hypothetical vignettes, each of which portrayed some form of existential suffering (i.e., uncertainty-related anxiety, guilt feelings, and dependency-related meaninglessness) that has been repeatedly observed in terminally ill patients. Using a 6-point Likert-type scale (i.e., absolutely not effective to strongly effective), respondents were asked to rate the effectiveness of each intervention for each of the three hypothetical situations.

Hira and colleagues (2003) reported three main findings. First, factor analysis identified six major categories into which interventions could be sorted: (a) a meaning-

centered approach, (b) a supportive-expressive approach, (c) a religious approach, (d) education and coping skills training, (e) the provision of comfortable environments, and (f) methods promoting a sense of “being” (e.g., sharing time, being in-the-moment). Second, professionals rated the effectiveness of specific interventions differently according to the hypothetical situation. For example, psychologists evaluated a supportive-expressive approach (e.g., acceptance of and respect for the patient, active listening, attentiveness, and reassurance as to the normality of feelings) as significantly more effective than psychiatrists did. And third, evaluations of specific treatments were associated with the participants’ professional status. For example, palliative care nurses rated the supportive-expressive approach, the meaning-centered approach, methods promoting a sense of well-being, and the provision of comfortable environments as being more effective than did psychiatrists, who tended to favour psychopharmacological therapies. See Appendix B for a complete list of the categories and interventions.²

Hirai and colleagues (2003) also reported that the majority of professionals surveyed recommended that patients be assessed as to the specific nature of their suffering and offered a treatment intervention tailored to their unique needs.

Existential Psychotherapy

Existential psychotherapy is probably best described as a *philosophical approach* to therapy rather than a set of specific techniques. The basic assumption of existential psychotherapy is that “ultimate concerns” of human existence, which Yalom (1980) described as the “givens” (i.e., death, freedom, isolation, and meaninglessness), underlie many of the problems faced by individuals. Yalom described these ultimate concerns as an inescapable part of human existence, which create inner conflicts (e.g., anxiety) within

an individual when confronted with death and loss. For the dying and their families, these concerns are of great importance.

Freedom

Two important aspects of freedom in existential psychotherapy are responsibility and motivation. From the existentialist's point of view, freedom refers to being able to create one's own destiny and continually re-define oneself within a given environment. At the same time however, inner conflicts and anxiety may arise when specific events remind us that we are solely responsible for our destiny and our perceptions of the world. A main task of existential therapy is to help clients gain insight into and acceptance of their current situations in life and motivate them to move toward their goals (Yalom, 1980).

Isolation

Yalom (1980) described existential isolation as the loneliness that people feel when they become aware that no matter how close they feel to other individuals, they will always be alone in the world. Humans have an innate need to relate to others for survival, and the awareness that we are truly alone tends to cause anxiety. An individual who confronts death through a diagnosis of a terminal illness will become acutely aware of the true existential feeling of isolation. Existential psychotherapy is designed to help clients experience feeling alone with tolerable levels of anxiety and to understand that both this experience and the anxiety that accompanies it are natural and necessary in life.

Meaninglessness

According to the existential perspective, human beings require meaning in life to maintain psychological health. For example, Frankl (1959) suggested that the

fundamental human quest in life is the search for meaning. Yalom (1980) claimed that unless or until we are able to make meaning of our surroundings or situations in life, we will experience anxiety. The search for meaning is especially salient for those facing imminent death.

Existential Defense Mechanisms

To repress the anxiety associated with the awareness of mortality, individuals may employ a variety of psychological defense mechanisms, such as an irrational belief in one's immortality or the existence of an ultimate rescuer who will protect them from death. According to Yalom (1980), these defenses may provide "safety nets" against anxiety, but when individuals realize that their guardian angels are not real and are not going to rescue them from death, they are left with raw fear and anxiety in the present and also for the future. These "safety nets" may also inhibit growth towards understanding and experiencing healthy, adaptive, existential suffering. An example of "healthy" existential suffering is feeling free to live the remainder of one's life to its fullest, despite the fear associated with impending death. The focus switches from how and when one will die to how one can achieve quality of life in the "here-and-now."

Existential Techniques

Existential therapists utilize an eclectic mix of techniques from other theoretical perspectives in their work with terminal patients. This approach places great emphasis on the client-therapist relationship as the means of change and because it is collaborative in nature, both client and counsellor benefit and gain insight from the process (van Deurzen-Smith, 1998). That is, both participants are confronting existential concerns and each may gain insight from the other, which can create a unique bond between them (Jacobson,

2003). Some of the main goals of existential therapy are to help clients to (a) engage and be fully present and authentic in life, despite the circumstances; (b) acknowledge and confront the “ultimate concerns” of human existence head-on; and (c) develop strategies to manage the anxieties that coincide with these concerns (Bugental, 1990).

Application to Dying Individuals and Their Families

Existential psychotherapy may help the terminally ill find meaning in their life, illness, and death, and it may reduce their anxiety to a more manageable level. This may help them reclaim some control over their situation and be able to live life more fully in the present. It may also help family members organize their thoughts and address the issues that accompany death and dying. However, it should be noted that existential therapy might not be helpful or appropriate for some populations. For example, existential psychotherapy promotes self-awareness, self-responsibility, self-acceptance, and self-determinism, and in some religions and ethnic cultures, such self-exploration is not encouraged (Vontress, Johnson, & Epp, 1999).

Dignity Therapy

Helping patients achieve and maintain a sense of hope or dignity as they face a progressing terminal illness is a challenge for end-of-life care providers (Chochinov et al., 1998; Chochinov et al., 2005a; Chochinov et al., 2005b). For example, Wilson and colleagues (2004) found that patients rated “loss of dignity” as an even more concerning issue for them than pain and symptom management. Dignity therapy addresses some of the issues that patients identify as being most important as death draws near (e.g., maintenance of pride, that life has stood for something, maintaining a sense of self, worries of becoming a burden, role preservation, loss of independence, demeaning

attitudes of others) (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Chochinov et al., 2005a).

Dignity therapy invites patients to talk about things that matter most to them (historically and presently) and for what they would like to be most remembered. It is “designed to engender a sense of meaning and purpose, thereby reducing suffering in patients nearing death” (Chochinov et al., 2005a, p. 5521). Chochinov and colleagues (2005a) devised a list of possible questions that therapists can give patients to think about, and then after ample time for reflection, audio-tape their responses. Questions pertain to the patient’s life history, highlighting important aspects (e.g., roles, accomplishments, hopes and dreams), any advice or guidance they would like to pass on, and any specific things they would like their loved ones to know about them. The questions provide a flexible guide for therapists to use, based on patients’ individual responses. The interview is then transcribed verbatim and edited by the therapist for clarity, sequencing of life events, and organization of pertinent information. The document is then read aloud to the patient for accuracy and feedback. For the patient, hearing his or her thoughts, feelings, and desires spoken aloud can be empowering, and the process may “bolster a sense of meaning and purpose while reinforcing a continued sense of worth within a framework that is supportive, nurturing and accessible, even for those proximate to death” (p. 5524). The patient also can offer this document to his or her loved ones as a gift.

Chochinov and colleagues (2005a) conducted a study of 100 terminal cancer patients to establish the practicality of dignity therapy and to examine its impact on psychosocial and existential distress. Dignity therapy was conducted with all participants

over the course of 1 – 3 sessions. Participants completed both pre- and post-intervention measures, rating their distress on a 7-point ordinal scale (i.e., 0 = not a source of distress to 6 = a source of extreme distress) as it pertains to anxiety, depression, desire for death, hopelessness, and suffering. As well, they completed a two-item, quality-of-life instrument (Graham & Longman, 1987) and a revised *Edmonton Symptom Assessment Scale* (Bruera, Kuehn, Miller, Selmsler, & Macmillan, 1991), which includes a measure of one's will to live. Participants also answered a post-intervention satisfaction survey to determine whether dignity therapy had an impact on them personally.

Qualitative analyses indicated that 91% reported feeling “satisfied” or “highly satisfied” with dignity therapy. Some participants indicated that dignity therapy helped them organize their thoughts, memories, and feelings into a coherent document that allowed them to visually “see” more meaning in their life. Overall, 81% indicated that this intervention was helpful for them and would be useful for communicating to their loved ones what is important to them.

Post-intervention quantitative analyses showed significant improvement on measures of suffering, depressed mood, and dignity. Patients who initially reported more psychosocial despair appeared to especially benefit from dignity therapy as compared to those who reported less despair. Dignity therapy also had a positive impact on quality of life, degree of subjective suffering, and thoughts of death. Overall, the results suggested that dignity therapy is a feasible and effective intervention to address the psychosocial and existential distress that many patients experience towards the end of life.

Life Tape Project (LTP)

The diagnosis of cancer is a devastating experience for patients and their families. For many, very little information is heard or absorbed after they hear the word “cancer.” To facilitate communication and understanding with his patients, oncologist Ernest Rosenbaum began to tape-record the initial office consultation during which the diagnosis of cancer and treatment plan are revealed (Rosenbaum & Rosenbaum, 1977, as cited in Rosenbaum et al., 2006). Family members are encouraged to attend, and an audiotape is given to the patient to take home, review, and discuss with others. Rosenbaum discovered unexpected benefits from this practice when feedback from his patients and their family members indicated that sharing the tape had helped them to talk freely with others about their thoughts and fears. As an added benefit, family members expressed that they felt included in this life-changing event, and all reported a strengthening of family cohesion as a result of the increased communication.

Rosenbaum expanded this concept to its current form, the LTP, which consists of a (free of charge) 1-2 hour videotape of his meeting with the patient and family members. The meeting focuses on how cancer affects them all, as well as the patient’s life story and family history. Before the meeting, an interviewer determines what specific topics are of most importance to the patient and family, and a list of possible questions is generated for the participants to reflect upon. During the interview, each member of the family contributes to the creation of an in-depth story about the patient’s life, and the videotape is then edited and given to the patient as a keepsake or legacy to be passed on to others (Rosenbaum et al., 2006).

The LTP is designed to create “symbolic immortality...a continuous chain of

life - where values, achievement, and philosophical thoughts are passed on to future generations, and thus some important part of the individual continues to exist symbolically, even after death” (Rosenbaum et al., 2006, p. 329). The intended benefits of LTP are to (a) bolster a sense of continuity by identifying what has been accomplished or created and what will be left behind; (b) increase self-observation by exploring the past and recognizing what has been worthwhile; (c) provide personal meaning by recognizing one’s uniqueness through personal and family history; (d) enhance self-respect by recognizing one’s importance to others; (e) create a symbolic immortality by leaving a lasting legacy; (f) foster dignity by viewing oneself as a worthwhile person with feelings, accomplishments, and passions independent of the illness; and (g) to promote a sense of closure by tying up loose ends in life and concluding unfinished business with family and friends (Rosenbaum et al., 2006).

Rosenbaum and colleagues (2004, as cited in Rosenbaum et al., 2006) conducted a study of 35 mature (60 years of age and older) cancer patients and their families to examine the benefits of the LTP as an existential intervention. Two weeks after they completed the LTP, participants contacted by telephone answered four open-ended questions (i.e., “What was the most important topic discussed? Do you view your family members differently because of the LTP?” “Have you benefited from the LTP?” “Has the LTP influenced your relationship with your family?”). The responses were transcribed, coded, and categorized into five categories by the frequency by which they were cited as a benefit. In general, the LTP was considered beneficial in that it provides (a) a legacy for passing on values and personal life philosophy (64%); (b) a better understanding of self (41%); (c) the opportunity to explore and connect to one’s roots (35%); (d) the ability to

communicate with family and friends and share feelings, fears, love, and appreciation (17%); and (e) a sense of peace by creating a family story to leave behind (17%). Overall, ninety percent of the patients reported significant benefits from the intervention, and ninety-five percent reported benefits in at least one category.

Finding Integrity and Meaning in Death

Frankl (1963) argued that “meaning can be found in life literally up to the last moment, up to the last press, in the face of death” (p. 76). Organ, tissue, and bone donation may be one way of making meaning of death for the dying person and his or her family.

Organ, Tissue, and Bone Donation

At the 2007 *Canadian Society of Transplantation* (CST) annual meeting in Banff, Alberta, Dr. J. Gill reported that as of December 31, 2006, 4,265 patients were waiting for an organ transplant in Canada. The report also indicated that a total of 200 patients had died during the previous year while waiting for the life-saving procedure (*Canadian Organ Replacement Register*, 2007). Thus, there is a substantial gap between the need for and availability of vital organs for transplant.

Organ, tissue, and bone donation may offer profound meaning to both the dying individual and his or her family members. For patients on the receiving end, the transplant offers a second chance to engage in life’s opportunities and live life more fully. In a study of 20 organ recipients, Macdonald (2006) found that the transplant experience profoundly impacted them physically, emotionally, and spiritually. Recipients spoke about how it became necessary to “recognize and embrace both the fullness and the fragility of life....Most centrally, the recipients’ living with death is never entirely alone.

The life and body of another is always involved” (p. 61). The notion that this deceased companion was now conjoined with them provided comfort for some recipients in their struggle with life post-surgery and eased their anxiety about the threat of their own death. This perception of a new lease on life, however long it may be, compelled many recipients to want to “give back” (Sharp, 1995) in the forms of mentoring, advocating for, and becoming a donor themselves to pass on their experiences to others after they die (Macdonald, 2006).

From the dying individual’s perspective, the thought of giving life to save a life may be helpful in making meaning out of his or her own death. Knowing that one’s death may be able to help and be appreciated by others (i.e., the recipients and their families) may be comforting. Moreover, from the donor’s and family’s perspectives, organ, tissue, and bone donation may be viewed as a way of transcending death as the individual “lives on” in the body of another (Dyer, 2004).

However, donor eligibility may be limited by the nature of the potential donor’s specific illness. For example, several forms of cancer, such as leukemia, lymphoma, and multiple myeloma render tissue unsuitable for tissue donation (Calgary Health Region, 2007). Alternatively, organ, tissue, and bone from cancer patients can be donated for use by researchers or educational institutions, or the entire body can be donated for research (University of Calgary, 2007).

Employing Helpful Activities

Employing subjectively meaningful practices may help the terminally ill, their families, and others involved with their care navigate some difficult issues with the advancing illness and impending death. The following is a summary of ways in which

individuals may (a) acknowledge or deny what the illness will bring; (b) learn how to say goodbye; (c) work together as a group towards a dying wish; or (d) allow the dying to have some control over events after death.

Open Communication Versus Allowing Denial

A common assertion in the grief literature is that families who have open communication generally handle deaths better than those who do not (e.g., Bertman, 1980; Cavalli, Hansen & Kaye, 2004). Chochinov, Tataryn, Wilson, Enns, and Lander's (2000) survey of 200 cancer patients found that depression was nearly three times greater in patients who did not openly acknowledge their prognosis, as compared to those who fully or partially acknowledge their prognosis. Encouraging communication about fears, prognosis, treatment options, and what the future may bring may help reduce anger, anxiety, and feelings of loss, guilt, irritability, and sadness in some individuals, both pre- and post-death, and may foster support-seeking behaviours. Open communication may also be instrumental in alleviating anticipatory grief, which is the process by which the dying and their family and friends face the loss before death has occurred (Casarett, Kutner, & Abrahm, 2001).

However, open communication and acknowledgment may not be suitable or desirable for everyone. As Chochinov and colleagues (2000) also suggested, for some, denial may be "a common mechanism of defence in the emotional adjustment to cancer" (p. 500). Kreitler (1999) argued that denial may even have a positive effect for some patients (e.g., in reducing anxiety) when they first learn of their diagnosis, as well as in the terminal stage.

Callan's first-person account of her mother's death from cancer is one example of how open acknowledgement and communication may not always be appropriate (Callan, 2001). Callan's mother seemed to be coping with her diagnosis of terminal cancer well enough, through a characteristic form of denial. With grace and dignity, and by consistently maintaining that everything "is fine, just fine," she was helping herself and her children find the strength and courage to deal with the reality of the disease and her impending death. This was, however, until a well-meaning doctor insisted that she, as with all his patients, openly acknowledge her imminent death before he would assign her a bed in his ward. The poor woman's defences were shattered and her family watched in horror as the doctor exposed their mother's private illness to everyone in the room. Callan described how everyone in her family died a little that day, and she argued that her Mom's right to die a dignified death had been taken away from her. This doctor's "medicalized" policy of open communication did not take the needs or wishes of the family into consideration; in fact, it found their needs "to be less important than hospital policy" (p.12). This example illustrates how denial may be a useful, meaningful practice for some families.

Cultural Practices

Bourgeois and Johnson (2004) described various cultural practices and rituals that have the potential to help individuals cope with their fears and anticipatory grief. They may help support the dying by making them feel less isolated, strengthening their relationships with others, assisting with a sense of closure, and helping caregivers to understand the dying person's wishes and preferred means of farewell.

Farewell Party

Bourgeois and Johnson (2004) described the “farewell party” as an event that offers a supportive environment to say goodbye, openly grieve with others, achieve a sense of closure, and to share in the experiences associated with dying. It also sends the message that the dying person and his or her family and friends view the impending death as a “normal” life event that can be shared by all those who want to take part in it.

Blanket Making

In this ritual, the dying person, family members, and friends can share stories and experiences as they work together to make a blanket for the deceased. Bourgeois and Johnson (2004) argued that the process of construction is far more important than the end product – for the dying, as well as all others involved. This practice provides the opportunity for the dying to openly discuss their wishes for what they want to happen after their death (e.g., funeral ceremony specifics), and helps to ensure that their wishes will actually be carried out. For example, the dying individual can express what clothes he or she wants to wear for the viewing (if applicable), or have input into the eulogy.

These examples illustrate how death rituals and practices can be “normalized” in the anticipation of death. The decision-making (e.g., who will prepare the body, what clothes will be worn, hair, makeup) allows the dying individual to maintain some control over the upcoming events, and fosters a sense of empowerment over and acceptance of the anticipated death. The family, in turn, also feels a sense of empowerment as they strive to ensure that their loved one’s requests will be honored (Bourgeois & Johnson, 2004). Although not everyone embraces an attitude of death acceptance, it is important for health professionals to understand the influence that culture can have on the dying

individual and his or her family and friends. They might be in a position to help individuals feel less isolated and more supported in their journey towards end of life. This may result in “where the grief experienced is uncomplicated and progresses in a manner comfortable for the persons involved” (Bourgeois & Johnson, 2004, p. 104).

CHAPTER 5

Psychological Interventions and Supportive Strategies

The following selected interventions are designed to help individuals find meaning in their experiences, as well as manage anxiety, reclaim some control, and face the prospect of death with dignity.

Cognitive Behavioral Therapy

Cognitive behavioural therapy (CBT) is a blend of cognitive approaches (e.g., Beck, 1976) and behavioural techniques (e.g., Yates, 1970). The cognitive perspective assumes that thoughts influence emotions and behaviours; thus, if individuals can change the way they think, their behaviors will change as well. Behavioural theory focuses on environmental consequences and reinforcements as the driving force behind behaviours.

Cognitive Therapy

According to this approach, thoughts are organized in a hierarchy. It is assumed that the sequencing of thoughts begins with core beliefs, which influence intermediate thoughts, which influence automatic thoughts, which in turn influence behaviour and emotions (Beck, 1976, 1987, 1995; Beck, Rush, Shaw, & Emery, 1979). Basic core beliefs (cognitive schemas), which are our assumptions about our identity in the world, are derived from personal experience and identification with significant others in early life. As we develop, these core concepts become ingrained with our perception of “self” and influence the formation of other beliefs, values, and attitudes. Thus, our core beliefs influence our perceptions of events in the environment. We make assumptions (intermediate thoughts) based on these perceptions, and these assumptions influence our behaviour and emotions (Beck, 1995). For example, an individual whose core belief is

that he or she is not a “good person” may assume that he or she is not worthy of being loved by others and may behave in ways that reinforce his or her basic belief, such as not establishing meaningful relationships with others. Cognitive therapists begin by helping clients identify their core beliefs about self (cognitive schemas). This is considered necessary to change intermediate thoughts and subsequent behaviour (Beck, 1995; Beck, et al., 1979).

A few examples of cognitive distortions that unconsciously influence our thinking are blaming, overgeneralization, and polarized thinking. With respect to individuals with terminal diseases, these distorted styles of thinking may undermine effective coping and management of serious illness (Lain, 2007). In blaming, individuals either hold other people responsible for all their pain and troubles or they blame themselves for everyone else’s problems. Examples of blaming: “I am suffering because nobody understands, or cares, how devastating this is for me.” “My illness is destroying my family and they would be better off without me.”

Individuals who engage in overgeneralization tend to come to a general conclusion on the basis of a single piece of evidence, assume that the outcome will occur over and over again and in other situations. An example of this way of thinking is, “My pain kept me awake all night last night. I will never have a sound sleep again.”

In polarized thinking, individuals interpret events as all-or-nothing extremes. That is, they perceive events in either black or white, with no middle ground. An example of this way of thinking is, “I used to have a perfect life. Now I have cancer. My life is a disaster.”

The primary goal of cognitive therapy is to identify and correct maladaptive assumptions that lead to and maintain maladaptive automatic thoughts, and which, in turn, generate negative emotions and self-defeating behaviours. Once a maladaptive assumption has been identified and acknowledged, it can be challenged and modified. By teaching individuals self-monitoring skills that help them recognize their maladaptive automatic thoughts, they can then use them on their own, outside of therapy (Beck, 1995).

Beck and colleagues (1979) break down cognitive therapy into five distinct stages, in which clients (a) learn to self-monitor their negative thoughts; (b) recognize how thoughts, feelings, and behaviours are interconnected; (c) challenge the credibility and reality of distorted automatic thoughts; (d) substitute reality-based thoughts in place of distorted automatic thoughts; and (e) learn to identify and modify beliefs that cause them to distort their experiences.

Behaviour Therapy

The behavioural approach began in the 1950's, and according to Spiegler and Guevremont (1998), it challenged the notion that cognitive processes are the driving force behind behaviour. Rather, theorists from this perspective argued that behaviour is the result of learning and environmental reinforcements. More recently, cognitive processes are used in tandem with behavioural techniques to modify problematic behaviours. Contemporary behaviour therapy involves three main approaches:

(a) *Behaviour modification* is based on Skinner's (1953) theory of operant conditioning, which assumes that behaviour is a function of its environmental consequences. Treatments such as reinforcements are utilized to change a behaviour by

changing its consequences. Positive reinforcement strengthens behaviour by increasing the frequency of a response that is followed by a desired event (*positive reinforcement*). For example, to the extent that engaging in deep breathing exercises results in feeling of relaxation, deep breathing behaviour will be strengthened. *Negative reinforcement* also strengthens a behaviour, by increasing the frequency of a response that is followed by the avoidance or moderation of an aversive event or state. For example, individuals who have lost their hair to chemotherapy treatments may avoid going out in public to avoid feelings of anxiety and embarrassment as others notice the hair loss. In *punishment*, an aversive event follows a specific response; thus, there is a decrease in the occurrence of that response. For example, if family members and friends openly disapprove of overt grief behaviours, the grieving individual is likely to suppress his or her emotions and stop talking about the deceased altogether. This, in turn, may cause the individual to become “stuck” within his or her grief, and lead to possible future problems.

(b) The *stimulus response* (S-R) model draws from the principles of classical conditioning (Pavlov, 1927), which assumes that behaviours are “learned” by the creation of associations between previously neutral stimuli and distressing events. For example, for a cancer patient who is undergoing chemotherapy treatments at a hospital, walking into the hospital may gradually become associated with the experience of feeling ill during treatments and result in the individual feeling ill when walking through the hospital door. According to the S-R model, the learned behaviour can generalize to entire classes of stimuli and distressing events once a relation is established between a situation and a traumatic event (Wasserman & Miller, 1997).

(c) Psychologist Albert Bandura is credited with the development of the *social learning theory*, which he developed in reaction to Pavlov's (1927) theory. Bandura (1977) rejected the strict view that behaviour is based simply on stimulus and response. Instead, he argued that psychological functioning is influenced by reciprocal interactions among three primary influences: behaviour, cognitive processes, and environmental factors (Bandura, 1977). The social learning approach also assumes that people are capable of mastering a situation and can bring about self-change (i.e. self-efficacy) (Bandura, 1982).

Behaviour therapy involves techniques such as exposure therapy, behavioural rehearsal, role-playing, and diversion techniques (Lazarus, 1971). Behavioural approaches may also include relaxation techniques, such as breathing exercises and progressive muscle relaxation (Bryant, Sackville, Dang, Moulds, & Guthrie, 1999). Contemporary behavioural techniques are action-oriented; for example, clients are encouraged to monitor their problem behaviour(s), learn and practice new coping skills, and role-play social learning.

CBT therapists utilize a blend of behavioural and cognitive techniques. Cognitive treatments complement behavioural approaches in that they target and change maladaptive thoughts, which contribute to the problem behaviour. Behavioural treatments are designed to weaken the learned associations between events and negative mood states. Thus, CBT can help individuals change the way they think and behave, and to better understand the relationship between the two.

Application of CBT to Dying Individuals and Their Families

CBT can be especially useful for dying patients and their families, because for them, impending death is an unchangeable event. “Cognitive distortions related to death and dying can typically assume one of two forms” (Taylor, 2006, p. 143). Patients can either deny the severity or terminal nature of their condition, or they can exaggerate it and dwell on the worst-case scenario. Cognitive techniques may be helpful for patients and their families in coming to terms with the illness, and behavioural techniques (e.g., relaxation exercises) can be helpful in managing stress (Tatrow & Montgomery, 2006).

CBT may help to lessen the fears associated with the anticipated death, help individuals to view their situation from a more empowering perspective, and teach more effective coping skills. Several studies have found that CBT is effective in helping those who are experiencing complicated grief (Boelen, 2006; Boelen, van den Hout, & van den Bout, 2006; Matthews & Marwit, 2004). It can be offered to a wide range of populations with differing cultures, incomes, education, and background (Penedo et al., 2006). CBT can also be applied in a variety of settings (e.g., office, hospital room, or home through the Internet) (Wagner, Knaevelsrud, & Maercker, 2006) and it can be offered in the form of individual, family, or group therapy (Weinrach, 1988).

Family Systems Therapy

Family systems therapy is based on the assumptions that (a) individuals are best understood within the larger context of the family unit and other relationships, (b) the family unit is interactional (i.e., capable of influencing each other), and (c) assessing the interactions within the entire family will provide the whole picture of the family dynamics. The family systems approach draws from the principles of general systems

theory (von Bertalanffy, 1951), which purports that all biological organisms, extending from the cellular level to the human being, have a similarity or “isomorphy” in underlying structure. Each possesses a boundary and a power structure that keeps the unit safe and alive. Each unit or system (e.g., single cell, single human) operates within other systems (e.g., human social groups, human organizations, whole societies, the world) and stays viable by communicating in specific manners. The stability and longevity of the unit, or system, depends on a balance or “homeostasis” of energy within the system.

The development of the family systems perspective was influenced by Gregory Bateson, Jay Haley, Salvador Minuchin, and others, who argued that families also operate as unique interactive units, and each has their own set of rules and boundaries that helps maintain homeostasis. According to this view, what happens to one member within the family will have an effect on all the other members.

In a family system, each member learns the family’s rules and boundaries and each is expected to stay within those perimeters. Individuals who deviate from the unit’s set patterns are usually identified by other family members as “the problem,” and are targeted for therapy to be “fixed.” However, the “problem” individual may be only a scapegoat, who reflects the family’s overall dysfunction. Thus, “problematic” behaviour may (a) indicate the family is operating dysfunctionally, (b) serve some purpose or function for the family, or (c) have been handed down from previous generations (Akister & Reibstein, 2004).

Long-term goals in family therapy include helping families (a) enhance interpersonal communication; (b) allow individual members to feel accepted; (c) release the “problem” person from his or her role; (d) decrease the need for scapegoats;

(e) improve interpersonal understanding and empathy; (f) improve their ability to accept and deal with differences; (h) improve problem-solving abilities; (i) develop a more flexible idea of leadership by any family member; (j) improve monitoring of the internal functioning of the family; (k) improve individuation and autonomy; and (l) develop a balance between individual autonomy and family solidarity (Fuller et al., 1998).

One of the techniques used by family systems therapists is *joining* (Minuchin & Fishman, 1981). The therapist can either “join” the family by integrating himself or herself into the family unit as an “actor” to make contact with and gain the trust of the members, or join from a disengaged position and assume the role of “director” or expert. By joining as an actor, the therapist can communicate with all aged members of the family unit, interact with the family in a playful, relaxed manner, and present himself or herself as an authority who plays with children and addresses adults as parents (e.g., “Dad,” tell “Mother” what you are feeling when...”). By joining as a director, the therapist attempts to identify the family’s preferred “family dance,” meaning the set patterns in which family members communicate and behave toward each other. He or she then presents alternative scenarios, in which the family tries new ways of communicating and visualizing others’ perspectives.

Another technique is *boundary-making*. Therapists use boundary-making techniques to help family members to see other members’ perspectives from their unique points of view. An example might be introducing a “rule” at the start of therapy that “no person should talk for another person, or tell another person how this person feels or thinks” (Minuchin & Fishman, 1981, p. 149). This rule allows individuals to voice their own opinions and creates a boundary to prevent their psychological space from intrusion.

Application to dying individuals and their families

A terminal illness can be devastating to a family's functioning. Not only does it rob the life of a loved one, but it can also contribute to dysfunctional behaviour by family members, both pre-death and post-death. Fear, stress, exhaustion, and other issues associated with death and dying can place great pressure on a family, and some individuals may "deal" with it by avoidance, others by indulging in self-soothing methods (e.g., alcohol abuse), and yet others may become combative and abusive towards others within the family. Family systems therapy can be offered to the terminally ill and their families to help members find new ways of communicating their emotions and experiences. This communication helps facilitate an understanding that others may be sharing the same feelings or worries and they do not need to face fears, emotions, and the illness alone. The family may also begin to understand why individual members are acting the way they are and learn to deal with the pressures facing them in a supportive, united manner.

Family Systems Interventions

Family systems therapy with clients experiencing cancer focuses on encouraging family cohesion. Robinson, Carroll, and Watson (2005) used an "action" research design, in which participants were active collaborators in a process aimed at increasing their understanding of the current situation (Hult & Lennung, 1980), understanding how cancer affects families, and guiding the development of appropriate interventions. From data obtained from the four families involved, Robinson and colleagues (2005) identified three overarching themes underlying significant distress: (a) finding a balance between isolation and connection, (b) beliefs about the meaning of life and death, and (c) finding a

balance between one's previous world without cancer and one's current world with cancer. For example, some participants reported that their diagnosis suddenly isolated them personally, as they realized that they were all alone in undergoing cancer treatments and facing death. They also felt socially isolated as others pulled away from them, possibly due to discomfort with or fear of the illness, or because of uncertainty as to how to help.

Trying to find meaning in or make sense out of the cancer experience takes many on an emotional roller-coaster ride. Robinson and colleagues (2005) found that there are three polarities in the thoughts and behaviours of cancer patients struggling with the meaning of their cancer and how to deal with it: senselessness versus meaning, loss versus renewal, and important (yet mundane) versus essential. Some families turned to a spiritual realm in their search for meaning, whereas others succumbed to the perceived senselessness of the disease. Some participants indicated that it was easier and more comfortable to deny that cancer exists within the family than to deal with it directly. This can be problematic for several reasons. One is that the patient may not seek necessary treatment. A second is that important preparations, such as writing a will, putting one's finances in order, and saying goodbye to loved ones, may never occur. A third is that other family members may go unsupported in their needs and concerns. After the death, survivors may be unprepared to deal with the myriad of decisions that planning a funeral entails or dealing with the estate of the deceased. These added concerns might also negatively impact the grieving process. On the other hand, living entirely in a new world dominated by cancer can be overwhelming also, as family members struggle with

anticipatory loss and possibly pull away prematurely in an attempt to live without the cancer-stricken member in their lives (Kember, 2005).

Listed below are some strategies commonly used by family systems therapists in dealing with issues of cancer. They can be useful for the entire family.

Shared experience building. This strategy involves family members' sharing each other's understanding of what they are experiencing. Wamboldt and Reiss (1989, as cited in Robinson et al., 2005) claimed that this activity not only validates the differences among individuals, but can also increase family unity. As family members share the collective experience of cancer, they feel supported rather than devalued or ignored. When this is achieved, a shared experience of healing may also begin (Robinson et al., 2005).

Interactive psychoeducation. Another strategy of family systems therapy is to provide relevant educational information about specific cancer illnesses. Short "question period" sessions are offered to cancer patients and their family members, in which they can obtain information about what is "normal" regarding specific forms of cancer and the experience of living with it. These interactive, psychoeducational sessions help alleviate common fears that one is "not coping properly," or that they are "not doing it right" (Robinson, et al., 2005).

Putting cancer in its place. By helping the patient and family members identify the many things that cancer has taken from them and strategizing on how to reclaim at least some of those things, cancer can be "put in its place" (Steinglass, 1998, as cited in Robinson et al., 2005). For example, a common side-effect of chemotherapy is hair loss, which leaves some patients feeling unattractive. One way to address this loss is to buy a

wig, trendy hat, or head wrap. This solution may also be beneficial to family members if the patient feels better about himself or herself and is more willing to engage in family events or public outings. This strategy may be instrumental in bringing back some of the “old-world” normalcy that the family was experiencing prior to the cancer diagnosis.

The *Look Good Feel Better* workshops offered to women with cancer teaches easy ways to address appearance-related effects of cancer treatments, and in the process, helps them to reclaim their sense of self. Industry-trained volunteers boost the morale of cancer patients by offering invaluable tips on skin, nails, makeup application, and hair alternatives, which help women “transform back” to their former appearance. This transformation can be empowering, and it can help some people forget about their illness for a brief time (Foley, n.d.).

Structuring therapy. Robinson and colleagues (2005) identified three important components in structuring a therapy approach for cancer patients and their families. The first component is maintaining a here-and-now focus. Although families cannot change their past experiences, the past can inspire changes to be implemented in the present. For example, work and financial gain may have been more of a priority over family obligations before the cancer diagnosis, and a reorganization of priorities in the present may help identify new sources of meaning in life, such as children and other family relationships.

The second component is the use of marital sessions, because intimate issues are not generally addressed in (full-) family sessions. The third component is the timing of therapy. It is important to schedule the sessions around the patient’s treatment schedule. For example, some patients are extremely ill for the first 10 days after a chemotherapy

session, so booking the sessions shortly before undergoing a chemotherapy treatment may result in fewer sessions missed by the patient (Robinson et al., 2005).

Interpersonal Psychotherapy (IPT)

IPT is a short-term (typically 16 weeks), three-phase approach to counselling that is aimed specifically at relationships and how people communicate in them. The basic assumption of IPT is that psychological problems (e.g., major depression) are largely the result of communication problems, which arise from attachment insecurities (McBride, Atkinson, Quilty, & Bagby, 2006). In this approach, it is assumed that the quality of early attachment to a significant caregiver will have a later influence on how successfully an individual is able to separate from others, as well as how relationships will be maintained (Bowlby, 1980).

The “focus of IPT is on one or two of four interpersonally relevant problem areas: grief (complicated bereavement), interpersonal role disputes (conflict with a significant other), role transitions (life change), and interpersonal deficits (problems in initiation of and sustaining relationships)” (Hinrichsen, 2008, p. 2). In the initial phase, the goal is to identify the patient’s underlying issue(s) causing the problem(s) (i.e., to conduct an interpersonal inventory). In the intermediate phase, the goals are to educate the client on the problem(s) identified, explore possible solutions or interventions, and develop coping strategies for the client. In the termination phase, treatment progress is measured, and if necessary, the nature of future sessions is discussed (Hinrichsen, 2008).

Cancer treatments are typically a source of considerable psychological distress. Computer-based and telephone IPT can be an important source of support for patients and their families. The telephone has made access to treatment possible when patients are

unable to travel to their appointments for various reasons. Donnelly and colleagues (2000) described the goals of telephone IPT for cancer patients as (a) exploring how cancer impacts the physical, psychological, and social functioning of the patient and his or her loved ones; (b) psychologically preparing all for what is to come with the illness and treatments; (c) encouraging communication and helping to find ways to express and battle negative feelings; (d) enhancing communication and expression of affect; (e) supporting psychological defences (e.g., allowing denial); (f) fostering independence; (g) facilitating coping; (h) optimizing social support, and; (i) addressing practical problems.

Some patients have identified one psychological benefit from telephone IPT as being able to have a comfortable conversation with the therapist while not having to “dress up,” because their sessions are not face-to-face. Some patients are extremely self-conscious about the way they look due to their illness and treatment, and are grateful for not having to cover up (e.g., put on a hat/scarf or makeup) (Weenolsen, 1996). Patients also appreciate knowing that the sessions can be fit around their treatment schedules and how the patient is feeling at the time.

IPT may also be beneficial for the bereaved. For example, if unresolved grief is the presenting problem, the focus of IPT will be to facilitate the grief process. Here, the end goal of therapy is for the bereaved to re-establish relationships to fill the void created by the death.

Meaning-Centered Group Psychotherapy

Unlike other traditional cancer support-groups, which tend to focus on expressing emotions or developing a support network for clients, meaning-centered group psychotherapy is designed to convey information through experiential learning (Breitbart,

et al., 2004; Breitbart & Heller, 2002; Greenstein & Breitbart, 2000). Breitbart and Heller (2002) argued that learning takes place more effectively when it is connected to emotional experience. On that assumption, they developed a group intervention to help those suffering from terminal illness find meaning, purpose, peace, spiritual well-being, and hope as they approach the end of life.

This approach entails a mixture of experiential group exercises, open-ended discussions, assigned readings, homework, and feedback from group leaders, all designed to help individuals heighten their awareness and look for meaning in life despite their situation. For example, one exercise that targets a sense of meaning and purpose in patients is to answer the question, “How has cancer changed what’s meaningful in your life?” One homework assignment is to “tell the story of your life and indicate who (in the patient’s family) would want to read it.” This approach also encourages patients to think about messages or advice that they would like to leave as a legacy for those left behind (Breitbart & Heller, 2002).

Anxiety Reducing Interventions

To the extent that patients are able to relax their bodies and minds, they are more able to experience a break in the negative and often overwhelming issues that accompany terminal illness. In addition, patients who practice meditation and relaxation techniques may be able to accept their situation in a more positive light and find meaning in their illness and death. Family members may also benefit from taking a “timeout” to practice the techniques, to the extent it helps prevent caregiver burnout (Kristjanson & Aoun, 2004).

Hypnosis

Hypnosis is not a therapy per se - it is a technique that can be used in conjunction with any therapy. According to Marques (n.d.), although hypnosis is associated with the “strange and mysterious,” it is actually a natural state of altered awareness that most people experience once in a while, such as when daydreaming, listening to music, watching television, reading, or even driving a vehicle. Hypnosis is used for many purposes, including stress and pain management, developing emotional strength, and behavior modification.

Lioffi and White (2001) studied 78 patients with far-advanced cancer, using a combination of qualitative and quantitative research methodologies, to evaluate the effects that hypnosis has on their quality of life (QOL). Patients were randomly assigned to one of two groups, both of which received standard medical care (e.g., pharmacological management of pain and other symptoms and psychological support), but only the treatment group underwent hypnosis. The researchers administered pre- and post-intervention measures of QOL, anxiety, and depression. The treatment group also participated in a semi-structured interview, post-intervention, designed to measure the impact that hypnosis may have had.

Lioffi and White (2001) administered four, 30-minute sessions of hypnosis every week for four weeks. Arm levitations and “cloud fantasy” were used to induce a hypnotic state, and then patients were given post-hypnotic suggestions for symptom management and control (nausea, vomiting, insomnia, breathlessness, fatigue, anxiety, and residual pain). Participants also were given post-hypnotic suggestions for more effective coping strategies and enhanced feelings of self-efficacy. The researchers found that at the end of

the four-week trial, patients in the hypnosis group had significantly better overall QOL and lower levels of depression and anxiety, as compared to the control group. Results indicated that hypnosis reduced emotional distress, improved mental adjustment to the illness, and promoted more effective coping strategies. In addition, hypnosis was effective for decreasing “anxious moods, restlessness and anxious thoughts, depression, grief, demoralization, low self-esteem and pessimism” (p. 156).

Many writers have described the beneficial effects of hypnosis. For example, Benson, Arns, and Hoffman (1981) likened the hypnotic state to the relaxation response (Benson & Klipper, 1975), which is characterized by lower blood pressure and lower heart and respiratory rates. Similarly, Alderson (2004) suggested that induced relaxation can positively affect the body physically, emotionally, and cognitively, allowing for better functioning and concentration. From their meta-analysis of 18 studies on hypnotically-induced analgesia, Montgomery, Duhamel, and Redd (2000) concluded that hypnotic suggestion was effective in reducing clinical and experimental pain. See Appendices C, D, and E for examples of self-hypnosis techniques, suggestions for self-change, and using visual imagery with self-hypnosis.³

Progressive Muscle Relaxation

Edmund Jacobson, who first developed modern techniques of progressive relaxation, believed that one could reduce psychological anxiety by learning to relax physical tension in the body (Jacobson, 1978). Jacobson’s Progressive Muscle Relaxation (PMR) model is a two-step relaxation technique that involves tensing, and then relaxing, specific muscle groups of the body, one at a time, to release built-up stress and tension. By progressively targeting all the muscle groups, individuals can release stress and relax

their entire body. PMR, which can be done sitting or lying down, usually takes 20 minutes to work through the pre-recorded script. PMR is self-taught and therefore economical and available to many. See Appendix F for Jacobson's original PMR script (Jacobson, n.d.) and relevant websites.⁴

Breathing Exercises

For individuals who are not able to tense their muscles due to illness or injury, practicing deep-breathing exercises may offer the same anxiety-reducing results (Smith, 2001). See Appendix G for examples of stress-reducing breathing exercises.⁵

Meditation

Meditation is the act of looking deep into oneself to reach a stage of "being" in the present. Once in this stage, individuals become more conscious of what is happening within them by attuning to internal sensations and listening to their "inner voice." This simple act of taking time to be still and self-focused allows the body to rest and let stress hormones subside (Everly & Lating, 1950). According to Davidson and colleagues (2003), mindfulness meditation can stimulate brain activity and may enhance immune system functioning.

Meditation follows three basic steps: (a) focus or concentrate on a thing (e.g., a word, a sound) or an object (e.g., spot, visualization); (b) quiet the mind by acknowledging passing thoughts and then letting them pass by, always returning concentration back to the thing or object of focus; and (c) remain in the present experience and explore what is happening within the body without being distracted by thoughts and sensations outside of the body (Clement 2007; Shumsky, 2002).

Many studies have shown that meditation may improve the physiological, psychological, and spiritual health of those who practice it (e.g., Davidson et al., 2003; Kabat-Zinn et al., 1998; Smith et al., 2008). Carlson and Garland (2005) examined the effects of their 8-week Mindfulness-Based Stress-Reduction (MBSR) program on sleep, energy, and mood in 63 cancer patients. The 90-minute classes were offered at the Tom Baker Center in Calgary, Alberta, once a week. Activities consisted of body-scan meditation, sitting and walking meditation, hatha yoga, and 45 minutes of meditation homework for 6 days a week. Both before and after the intervention, participants completed the *Pittsburg Sleep Quality Index* (Buysse, Reynolds, Monk, Berman & Kupfer, 1889), the *Symptoms of Stress Inventory* (Leckie & Thompson, 1979), and the *Profile of Mood States* (McNair, Lorr, & Droppelman, 1971). Carlson and Garland found significant reductions in overall sleep disturbance, stress, mood disturbance, and fatigue, and significant improvements in sleep quality.

MacKenzie, Carlson, Munoz, and Speca (2007) also studied the effects of MBSR. Nine cancer patients participated in an 8-week program offered at the Tom Baker Centre and continued to attend weekly drop-in sessions after the program had ended. The purpose of the study was to explore self-perceived effects of MBSR on the lives of these cancer patients. Five major themes were identified in data collected from semi-structured interviews and a focus group. First, the participants indicated that they were more *open to change* after the program (e.g., in the way they viewed their illness, their coping abilities, and how they felt about their treatment and recovery). Second, practicing MBSR helped them with *self-control*. Participants indicated that they felt in better control of their bodies, both physically and mentally. Third, the *shared responses* from others regarding

their experiences provided a feeling of support and the courage to continue with treatments. Fourth, mindfulness meditation helped with *personal growth*. That is, the act of meditating provided participants with the “permission” to take the time to make sense of the chaos surrounding them, and allowed them to reconnect with their “self.” Fifth, participants reported that their “meditation practice began to meld with their other *spiritual* and religious practices,” (MacKenzie et al., 2007, p. 65) which, for some, was an unexpected surprise. See Appendix H for an example of a meditation that may be helpful in preparation for death.⁶

Guided Imagery

Tusek (2008) described this technique (also called *Guided Meditation*, and *Guided Visualization*) as a well-validated, stress-reducing tool for promoting a sense of peace and tranquility during a stressful or difficult time. It is closely related to hypnosis, in that a script is used to generate vivid images in users, which are specifically designed to help them relax.

Guided imagery is based on the assumptions that the activity of the mind and the body affect each other, and that imagery created in the mind stimulates the brain, producing beneficial changes. This, according to Neimark (1998), is because our thoughts and feelings are chemical in origin. When we vividly imagine walking on a beach and feeling the warmth of the sun, our body produces neuropeptides, which are chemical messengers. The increase in neuropeptides causes positive changes in our endocrine, nervous, and immune systems.

Guided imagery can be practiced alone (e.g., using a CD), with a partner or instructor (who reads a script aloud) reading a script, or an individual can record his or

her own voice recording (Benjamin, 1994). See Appendix I for a guided imagery script and relevant web sites.⁷

CHAPTER 6

Needs of the Bereaved

After the loved one has died, the needs of family members and caregivers may change. Here, the focus of care is on the survivors.

Grief

The word *grief* comes from the Latin, *gravare*, which means “to burden” or “to cause distress.” Grief is described as the normal process of reacting to a loss, which can be experienced physically (e.g., the death of a loved one), socially (e.g., through divorce), occupationally (e.g., losing a job), or materially (e.g., a change in financial status) (Dryden-Edwards, 2004). Emotional reactions can include anger, anguish, anxiety, despair, guilt, and sadness; in fact, there is no emotion (or lack of emotion) that cannot be considered part of “normal” grief. Physical reactions can include changes in appetite, illness, physical problems, or sleeping problems (Dryden-Edwards, 2004).

In this paper, “grief” refers to typical personal feelings in reactions to the loss of a loved one through death; “bereavement” refers to the objective state of having experienced that loss (i.e., state of sorrow); and “mourning” refers to the outward cultural expression(s) that individuals display to others in reaction to the loss (e.g., wearing specific colours of clothing) (Dryden-Edwards, 2004).

Theories of Grief

Although grief is a global phenomenon with many universal symptoms and behaviours, Breen and O’Connor (2007) cautioned that it is also highly subjective in nature. It is influenced by a multitude of factors, including personality, gender, age, culture, environment, who died (e.g., child, parent), and type of death (e.g., anticipated or

unexpected). Thus, the theories of grief presented below may generalize only to the populations from whom the theories were developed (e.g., primarily white, North American, middle-class, adults) and the nature of death is usually related to cancer.

Many specific models have been developed to describe how bereaved individuals move through their grief. Traditional models have focused on (a) symptom clusters (e.g., Lindemann, 1944), (b) grief work (e.g., Freud, 1917/1957; Bowlby, 1961, 1970, 1980); (c) stages of grief (e.g., Kübler-Ross, 1969), (d) phases of grief (e.g., Parkes, 1983); and (e) tasks of grief (e.g., Worden, 1991). More recent models include a biographical model (Walter, 1996) and a dual-process model (Stroebe & Schut, 1999).

Symptom Clusters

Lindemann's (1944) model of acute grief (i.e., reactions immediately following a loss) is based on his observations of (a) psychoneurotic patients who lost a relative during the course of treatment, (b) relatives of patients who died in the hospital, (c) bereaved victims and relatives of the Coconut Grove Fire, (in Boston, 1942), and (d) relatives of fallen members of the armed forces. Lindeman identified five typical "symptom" clusters in acute grief, which do not necessarily occur in a specific order. Note that Lindemann's use of the term "symptom" connotes illness or pathology; most current theorists eschew this term, preferring the term "reactions."

The first cluster of symptoms that Lindemann observed consists of somatic states, such as feelings of tightness in the throat and shortness of breath, which occur in waves and are triggered by events or memories of the deceased. The second cluster includes alterations to the sensoria, which produce feelings of unreality, increased emotional distance and isolation from others, and preoccupation with images of the deceased. The

third cluster comprises a strong preoccupation with feelings of guilt and responsibility concerning the death. The fourth cluster includes inexplicable feelings of hostility towards others, and the fifth cluster includes difficulties in performing daily activities due to feelings of restlessness and apathy. Lindemann (1944) concluded that the individual's "grief reaction... [is resolved upon successful] emancipation from the bondage to the deceased, readjustment to the environment in which the deceased is missing, and the formation of new relationships" (p. 143).

Grief Work

Freud (1917/1957) coined the term "*grief work*," to refer to the survivor's need to sever the bond of attachment to the deceased. Freud emphasized that the deeper the relationship between the two individuals (i.e., the stronger the attachment), the more difficult it is to sever the bond. Freud believed that to achieve a "successful" grief resolution, the bereaved must go through a long series of confrontations with the reality of the loss, until its power to overwhelm the individual with anxiety and sadness is diminished. For example, one might have to smell the deceased's favorite perfume over and over again, until the individual could smell the perfume without becoming overwhelmed by emotion. Freud argued that unless this attachment to the deceased is dissolved, the bereaved will not be able to form any future attachment to or relationships with others. Freud emphasized that grief work is time-consuming, hard work, due mainly to resistance to letting go of the attachment with the deceased. Bowlby's (1961, 1970, 1980) attachment theory gives one explanation as to why this is so.

The basic assumption of Bowlby's (1961, 1970, 1980) attachment theory is that infants are born with a need to attach to human figures for protection, security, and

nourishment necessary for survival. Specific behaviors are designed to bring the caregiver into close proximity and thus, satisfy the infant's needs (e.g., to be fed). Initially, this instinctual system means that the infant will behave in similar ways with any caregiver for nutrition, safety, and survival. Over the course of healthy development across the first 18 months of life, the infant will eventually develop an attachment (bond) to a preferred primary caregiver (attachment figure), seek proximity, and cling to this caregiver when danger is near or when nurturance is desired.

According to attachment theory, when there is a perceived threat to the safety and security of the primary relationship (e.g., a separation), instinctive behaviours are activated (e.g., searching) in attempts to bring back proximity and the feelings of safety and security (Bowlby, 1970). If the threat or situation is not resolved, anxiety and emotional distress (e.g., yearning, depression) may result. Attachment theory is helpful for understanding what happens when close bonds with others are threatened or broken. Adults experiencing such a loss tend to revert to the instinctual behaviours of searching and yearning that infants display when they are separated from their mother or caregiver. When this bond is involuntarily broken due to terminal illness or death and there is no chance of returning to the safety and security of the relationship, the distress of loss and grief may be overwhelming (Boelen et al., 2006).

Stages of Grief

The basic assumptions of all stage theories are that the stages are universal and sequential and that each stage is necessary for successful resolution of subsequent stages. Kübler-Ross' (1969, 1981) work with dying individuals led her to develop a five-stage model of coping with a terminal illness (i.e., denial, anger, bargaining, depression, and

acceptance). As well, the model has been adapted by many professionals as a framework for interpreting the grief process.

Although Kübler-Ross never made such claims, her model is often interpreted as implying that all dying people go through all of the stages she identified in a specific order and that achieving acceptance is essential, psychologically. However, Cutcliffe (2006a) described the process of moving through the stages as “analogous to the movement of the in-coming tide. While such a tide has a gradual progression towards its final destination, its progression is cyclic with many movements ‘out’ or ‘back’ before the end is successfully achieved” (p. 600). In other words, some dying or grieving individuals oscillate back and forth through bargaining and denial as they work towards acceptance or resolution, and as Cutcliffe also observed, many never move completely into acceptance at all.

Phases of Grief

Much of the literature on “phases of grief” is based on the contributions of John Bowlby and Colin Parkes. Following from Bowlby’s (1961, 1970, 1980) research in early attachment and primary relationships, Parkes (1972, 1983) proposed a phase theory of how the bereaved return to feelings of safety and security again (homeostasis) as they resolve their grief. Parkes focused on how people process information, and he proposed that the bereaved use a “*filtering*” system to let through or filter out unwanted information. According to Parkes, the process of grieving is an overall process of *realization*, in which the individual comes to terms with the reality of the loss.

Parkes (1972, 1983) argued that the bereaved must progress through four overlapping phases of grief before the process of realization is complete. In the first

phase (shock and numbness), individuals have difficulty comprehending and believing that the death has occurred. They feel stunned by the impact of the loss. In the second phase (yearning and searching), they may refuse to acknowledge the loss and attempt to return things to the way they were, pre-loss. They search for the deceased, trying to bring the deceased back into close proximity to relieve their feelings of separation anxiety. Alternatively, they may refuse to allow the belongings of the deceased to be moved, simply yearning for them to return home and find things just the way they should be. When the individual realizes that this is not possible, feelings of frustration and anger may result. In the third phase (disorganization and despair), the person is easily distracted, has trouble focusing and concentrating, and may become depressed. It is in this stage that the survivor comes to realize that the deceased is not coming back and this recognition leaves some individuals confused, fearful, and uncertain about their future. In the fourth phase (reorganization and recovery), the individual realizes that life continues without the deceased and begins to rebuild life without them.

As with stage versions, phasal models of grief should be regarded only as descriptive, as opposed to prescriptive, guidelines. Not all individuals show signs of moving through all of the phases or in the sequence described.

Tasks of Grief

In contrast to phase and stage models of grief, Worden (1991) argued that grieving survivors must work through a series of tasks to reach resolution. Here, once again, there is no set sequence to achieving the tasks. Worden's model has similarities to Freud's concept of "grief work," in that emotional investments need to be withdrawn from the deceased and reinvested in other relationships and activities. However, it differs

from Freud's in that it does not require breaking "all" bonds with the deceased. It involves modifying one's relationship with the deceased in such a way that it remains satisfying but reflects the changed circumstances (i.e., living in the present and able to move forward). Both theories also tend to be somewhat prescriptive in nature, emphasizing what grieving individuals "should" do. According to Worden, survivors must (a) accept the reality that the loved one has died, (b) experience and work through the pain, (c) adjust to life without the deceased, and (d) reinvest in new relationships and move on with life.

Worden's first task is for the individual to accept the reality of the loss at intellectual, emotional, and spiritual levels. Some individuals deny that the death has taken place and insist that possessions belonging to the deceased be kept exactly how they were when the death occurred. Some remove all reminders of the deceased and pretend that they never existed, whereas others employ psychic mediums to stay connected with the departed. According to Worden, individuals who have mastered this task understand that the deceased is not coming back, and thoughts have turned to, for example, hoping that the deceased will be "okay in heaven."

The second task in Worden's model is to identify, experience, and work through the pain of grief, and then release it. Here, bereaved individuals are able to realize that what they are feeling is normal and can understand that they will get past their pain by allowing emotions to surface. Individuals who successfully work through this task are able to talk about the deceased without feeling heavy, emotional anguish (Worden, 1991).

Worden's third task involves accepting a new identity role and adjusting to a new life and environment without the deceased (e.g., assume responsibilities previously taken

by the deceased). Thus, individuals who have achieved this task are able to negotiate everyday activities of life without the deceased (e.g., cook, pay bills, care for children) (Worden, 1991).

The fourth task in Worden's framework is to redirect some of the emotional energy invested in the deceased and reinvest it in another relationship. In this task, individuals retain an appropriate (i.e., altered) place for the deceased in their emotional life and make room for future relationships (Worden, 1991).

Recent Theoretical Frameworks

Biographical model. Walter (1996) rejects the dominant models of grief, which tend to focus on the necessity of working through emotion and separation to reach grief resolution. Instead, Walter believes that the bereaved typically want to talk about the deceased and share their memories with others. Walter contended that the purpose of grief is to reconstruct a new identity by creating a (new) life story that includes the deceased, and that interpersonal communication is the process by which this is done. Walter developed his biographical model to assist the bereaved in their mourning, by moving on "with" (as well as without) the deceased.

Dual-process model. Stroebe and Schut's (1999) model illustrates another new way of explaining how the bereaved cope adaptively with their loss. The dual-process model acknowledges a wide variability in grief responses. The authors assume that grieving individuals must work through their emotions and need to adapt to their altered world. Stroebe and Schut propose that the bereaved tend to cope with stressors (i.e. the loss, demands in the environment) by oscillating between two types of coping processes:

“loss-orientation” and “restoration-orientation.” Loss-orientation refers to coping with issues that are directly related to the loss (e.g., loneliness, sadness, helplessness), whereas restoration-orientation refers to coping with issues related to secondary changes brought on by the loss (e.g., financial, family demands), and adapting to these issues.

According to Stroebe and Schut (1999), loss-oriented coping behaviours (e.g., crying, talking about feelings) help individuals to work through their emotions. Restoration-oriented coping behaviours, such as learning new skills (e.g., how to balance a chequebook) or embracing a new identity (e.g., being a widower versus a spouse), helps the bereaved with distractions from their “loss” focus and to make adaptive life changes. Thus, the dual model suggests that the bereaved oscillate between confronting their stressors and taking breaks from their stressors. The model emphasizes that (a) at times, individuals may be more focused on coping with the loss itself, whereas at other times be more focused on adapting to an altered productive life, and (b) grieving may differ from one individual to another, from one moment to another, and from one culture to another.

“Normal” Grief Reaction Versus Complicated or Prolonged Grief

There is much debate over when “normal” (often termed “uncomplicated”) grieving becomes pathological (commonly referred to as “complicated” grieving) (Bonnano et al., 2007; Enright & Marwit, 2002; Horowitz et al., 1997; Maciejewski, Zhang, Block, & Prigerson, 2007; Marwit, 1996; Prigerson et al., 1995a; Rando, 1992; Zhang, El-Jawahri, & Prigerson, 2006). This is due primarily to the wide cultural variations in mourning customs; what members of one culture may view as a maladaptive grief reaction may appear as “normal” to members of another culture (Hayes & Kalish,

1987/1988). So what does “normal” or “uncomplicated” grief look like in North American culture?

Normal Grief

Prigerson and colleagues (1995a) observed that for most grieving individuals, grief reactions (e.g., crying, difficulty accepting the death, thinking about the deceased) diminish considerably between four and six months after the loss. Zhang and colleagues (2006) drew a similar conclusion from their literature review and described a normal grieving period as follows:

[B]y 6 months postloss, most bereaved individuals are able to accept the reality that the person has died, see the future as holding some potential for satisfying relationships, are able to engage in productive work, and capable of experiencing enjoyment. They are usually able to [find] some meaning and purpose in their lives, [maintain] emotional connections to others,...[and develop] new relationships and friendships....Bereaved individuals with uncomplicated grief reactions usually exhibit limited signs of impairment 6 months after the loss and appear able to adapt to their new situation. (pp. 1189-1190)

In contrast, Scott (n.d.) argued that although “acute” symptoms of grief generally wane somewhat after several months, some symptoms (e.g., sadness) may continue for longer than what is generally considered a “normal” length of time. For example, over time, individuals who have experienced painful anguish when thinking about the deceased may begin to notice that the intensity of the symptom(s) has diminished; however, they still experience sadness when thinking about the loss. McBride and Simms (2001) noted that

this experience may continue for months or even years. Scott (n.d.) suggested that the bereaved might identify a “benchmark” or a “guidepost” for themselves to indicate that they are progressing toward accepting the loss and moving on with life. By doing so, it may prevent them from feeling that they are not grieving like the “normal” majority.

Some researchers have observed that some individuals who have experienced a loss due to death do not show signs of overt grieving at all (e.g., Bonanno, 2004). Some even show positive emotion as a resilient way of dealing with their loss (Bonanno, 2004; Bonanno, Moskowitz, Papa, & Folkman, 2005; Bonanno, Wortman, & Nesse, 2004). Although these responses may not be considered by the majority as “normal” responses to loss, they can be useful and feel “normal” to those who employ them. As is the case when trying to determine a universal model of grief, it is difficult to describe what are “normal” grief responses.

In their longitudinal study, Maciejewski and colleagues (2007) identified patterns of typical grief symptom trajectories to determine whether there is a “typical” time frame for grief resolution. They based their two-year study on Jacobs’ (1993, as cited in Maciejewski et al., 2007) stage model of grief, which synthesizes and integrates the work of Bowlby (1961, 1980), Parkes (1972, 1983) and Kübler-Ross (1969). They concluded that “the normal response to loss progresses through the following stages: numbness-disbelief, separation distress (yearning-anger-anxiety), depression-mourning, and recovery....[and lasts] from 1 to 24 months postloss” (Maciejewski et al., 2007, p. 716).

Maciejewski and colleagues’ (2007) sample comprised 233 bereaved individuals (97% were white, 53% were 65 years and older) who had experienced the loss of a family member or loved one due to natural causes (e.g., cancer). Participants were interviewed at

an average of 6.3 months after the death of their loved one, again at an average of 10.9 months afterwards and finally, at an average of 19.7 months after the loss. The researchers examined the intensity, patterns, and consistency of five grief indicators: (a) shock, numbness-disbelief, (b) yearning or separation anxiety, (c) angry protest, (d) despair or depressed mood, and (e) acceptance and ultimate recovery. Frequencies and phases of grief indicators were assessed using the *Inventory of Complicated Grief-Revised* (Prigerson & Jacobs, 2001), which has a 5-point Likert Scale (1 = experiencing the grief indicator less than once per month to 5 = experiencing it several times per day). Depression was assessed using the *Hamilton Rating Scale for Depression* (Hamilton, 1960).

Results showed that most people experience the grieving process in roughly the same order predicted by Jacobs' model. The five indicators each tended to "peak" in intensity within the first 6 months postloss, and then slowly diminish in intensity over the subsequent 18 months. These findings were consistent with the assertion that symptoms may continue for months or years (McBride & Sims, 2001; Scott, n.d.). Specifically, disbelief tended to peak and then decline at 1 month, yearning peaked at an average of 4 months, anger peaked at about 5 months on average, and depression peaked at an average 6 months postloss. Acceptance climbed slowly and steadily over the 24 months studied. Somewhat surprisingly, Maciejewski and colleagues (2007) also found that "yearning, not depressive mood is the salient psychological response to natural death" (p. 721).

Maciejewski and colleagues' (2007) study provided the first empirical examination of Jacobs' stage theory and in so doing, provided a rough timeframe for "normal" grief, after which the reaction might be considered atypical. The authors

suggested that “[g]iven that the negative grief indicators all peak within 6 months, those individuals who experience...[persistence of] any of the indicators beyond 6 months post-loss would appear to deviate from the normal response to loss” (p. 721).

Complicated or Prolonged Grief

Grief reactions that are considered beyond the range of most people in terms of duration and/or intensity have been given many labels, including aberrant, abnormal, atypical, complicated, pathological (Horowitz et al., 1997; Zhang et al., 2006) and prolonged (Maciejewski et al., 2007). There are also many subtypes of complicated grief (CG) as well (e.g., chronic, delayed, distorted, inhibited, conflicted, and unanticipated) (Marwit, 1996). Many researchers over the years have argued for a separate category for CG in the DSM (e.g., Marwit, 1991; Rando, 1992). Presently, the DSM-IV-TR (American Psychiatric Association, 2000) advises that the length and expression of “normal” bereavement varies across different cultural groups. It also indicates that some individuals display symptoms that are similar to MDD (e.g., feeling sad, poor appetite, weight loss and insomnia), and if these symptoms persist longer than two months, a diagnosis of MDD should be made. As such, the DSM-IV-TR does not have a category for “abnormal” or “complicated” grief. However, it does specify several symptoms that are not characteristic of a “normal” grief reaction, which include:

- 1) guilt about things other than actions taken or not taken by the survivor at the time of the death; 2) thoughts of death other than the survivor feeling that he or she would be better off dead or should have died with the deceased person; 3) morbid preoccupation with worthlessness; 4) marked psychomotor retardation; 5) prolonged and marked functional

impairment; and 6) hallucinatory experiences other than thinking that he or she hears the voice of, or transiently sees the image of, the deceased person. (p. 741)

The literature reflects the differences of opinion on what exactly constitutes CG. Some researchers have argued that CG can be diagnosed by a separate set of symptoms (e.g., Boelen, & van den Bout, 2005; Prigerson et al., 1995a, 1999), whereas others have contended that the diagnosis should be defined by the duration of symptoms (Jacobs, 1993, as cited Maciejewski et al., 2007). Still others have insisted that CG is characterized by the extreme intensity of the symptoms (e.g., Horowitz et al., 1997), and some have argued that the diagnosis of CG should take into account the intensity, duration, and impairment of the symptoms (e.g., Goodkin et al., 2005-2006; Hogan, Worden, & Schmidt, 2005-2006; Maciejewski et al., 2007; Prigerson et al., 1995a; Zhang et al., 2006).

Both Enright and Marwit (2002) and Rando (1992) discussed the inconsistencies among various definitions of CG. They argued that some mental health clinicians may be mistaking other mental disorders for CG, and thus, prescribing inappropriate interventions for symptom relief. Others have argued that a separate *DSM* classification (i.e., a distinct disorder vs. a V-code) would provide a distinct set of criteria for atypical grief reactions, and clear up the confusion around symptoms that have surface similarities or disorders that frequently occur simultaneously, such as MDD and Post-Traumatic Stress Disorder (PTSD) (e.g., Bonanno et al., 2007; Marwit, 1991; Prigerson & Maciejewski, 2005; Shear, Frank, Houck, & Reynolds, 2005; Stroebe et al., 2000).

Maciejewski and colleagues (2007) prefer the term, *Prolonged Grief Disorder* (PGD) and defined it as follows:

PGD accurately describes a bereavement-specific mental disorder based on symptoms of grief that persist longer than is normally the case (i.e., >6 months post-loss....Furthermore, prolonged grief disorder permits the recognition of other psychiatric complications of bereavement, such as major depressive disorder and post-traumatic stress disorder.” (p. 721)

CG as a separate set of symptoms. There is some research to support the notion that CG symptoms are distinct from bereavement-related depressive and anxiety symptoms (e.g., Boelen & van den Bout, 2005; Prigerson et al., 1995a). For example, Prigerson and colleagues (1995a) pointed out that whereas depressive symptoms may include hypochondria, suicide ideation, psychomotor retardation, hopelessness or pessimism, anxiety, and insomnia, CG involves anger or hostility, being stunned by or disbelieving the loss, preoccupation with thoughts of the deceased, and yearning and pining for the deceased. Zhang and colleagues (2006) argued that whereas symptoms of PTSD include avoidance of reminders of the traumatic event and hyper-vigilance, CG involves separation distress due to issues of abandonment, mistrust of others, and difficulties forming new relationships. For example, individuals who are suffering from PTSD may avoid attending a family gathering due to fears that they may be attacked or harmed, whereas individuals suffering from CG may refuse to go to the gathering because they are angry with other family members for having “moved on” too soon after the loss or because they mistrust others’ loyalty to the deceased.

CG as duration of symptoms. Jacobs (1993, as cited in Maciejewski et al., 2007) argued that individuals should move through the stages of grieving within approximately a 6-month period. Therefore, they proposed that grief reactions that endure beyond that length of time should be considered a form of CG. Similarly, Zhang and colleagues (2006) contended that CG would be an appropriate diagnosis for symptoms that continue beyond 6 months, while Horowitz and colleagues (1997) indicated that symptoms present for more than a year after the loss would usually indicate CG. However, McBride and Simms' (2001) observed that the tasks of grieving may take up to 42 months (or longer) to complete. It seems that there is no consensus as to when, exactly, grieving may take a maladaptive turn, which suggests that perhaps "duration" of symptoms may not be a reliable indicator of CG.

CG as intensity of symptoms. The severity of the symptoms is of particular interest to those (e.g., Goodkin et al., 2005-2006; Hogan et al., 2005-2006) who argue that "normal" grief and CG simply represent different intensity levels of the same phenomenon. To collect data related to the diagnosis of CG, Horowitz and colleagues (1997) conducted a study of 70 bereaved adults between the ages of 21 and 55 years, who were mostly female, and who had lost their spouse or significant other within the previous 6 months. Participants completed the *Texas Revised Inventory of Grief* (Faschingbauer, 1981) and the *Reaction to Loss Inventory* (Horowitz & Field, n.d., as cited in Horowitz et al., 1997) at 6 months and 14 months, postloss, in which they rated the severity of each symptom on 5-point scales.

From their study, Horowitz and colleagues (1997) identified 30 grief reactions that seem to belong to three categories, which the researchers termed *intrusion* (e.g.,

emotional spells, thoughts about the cause of death), *avoidance* (e.g., avoiding thoughts or places that remind one of the deceased), and *failure to adapt* (e.g., feeling alone, empty, and that life is on hold) to the loss. From the broad range of reactions, Horowitz and colleagues extracted seven symptoms that showed a high degree of sensitivity and specificity in 41 % of the participants, which did not significantly overlap with symptoms of major depressive disorder, and of which did not significantly decline in the interval between 6 months and 14 months after the death. Thus, Horowitz and colleagues suggested that these reactions could be valid indicators of CG if they are still at severe levels at 14 months or beyond, postloss: (a) haunting thoughts of the lost relationship; (b) intense spells of emotions; (c) pining for the deceased; (d) feeling empty or completely alone; (e) avoiding things that remind them of the deceased; (f) unusual sleep disturbances, and (g) loss of interest in caretaking and social, professional, and recreational activities to a maladaptive degree. The researchers proposed that individuals who display any three or more of the seven symptoms at a level of intensity that interferes with daily functioning should be diagnosed with CG.

CG as symptoms, duration, and impairment. Building on Horowitz and colleagues' (1997) work and other research (e.g., Prigerson et al., 1995a, 1999; Prigerson 2004; Prigerson & Maciejewski, 2005; Maciejewski et al., 2007), Prigerson (n.d., as cited in *Complicated grief prolonged grief disorder: Criteria for prolonged grief disorder*, 2008), developed a set of diagnostic guidelines that she called *Consensus Criteria for Prolonged Grief Disorder*. These criteria represent a broader range of categories than do previous models, including (a) separation distress symptoms; (b) cognitive, emotional, and behavioural symptoms; (c) duration of symptoms; and (d) impairment in functioning.

According to Prigerson, individuals should be diagnosed with PGD if they are persistently experiencing (a) three or more symptoms of separation distress; (b) 5 of 9 of nine cognitive, emotional, and behavioural symptoms; (c) a symptom intensity that impairs daily functioning; and (d) symptoms of a duration of 6 months or longer from the onset of separation distress. See Appendix J for criteria for prolonged Grief Disorder.⁸

Grief in a Coupled Relationship

A common focus of couples and family systems therapy is on the dynamics of closeness and distance that occurs within a coupled relationship. Middelberg (2001) used the metaphor of “dance” to understand and illustrate the rhythms, patterns, and predictability of a couple’s relationship. Middelberg suggested that the relational dance is learned together, it is always in motion, and it is never ending. At times, it is performed gracefully and synchronically as couples move together, and at other times, it is poorly choreographed and clumsily executed, as one partner moves closer and the other moves away. Rosenblatt and Barner (2006) argued that the dance of closeness and distance is:

key to the chemistry of a relationship and to the dynamics of relationship change and stability. It is a focus of relationship system rules and relationship conflicts....[it] is present across all contexts of the relationship....[and it] is a constant challenge to dance in a way that works for both partners as individuals and for the couple relationship. (p. 279)

The death of a parent may complicate the dance of a couple’s relationship if grieving leads one partner to want more closeness and support from the other or to desire more distance from the other, and the other partner is not willing or able to provide it. Rosenblatt and Barner (2006) interviewed 18 couples, all in which one partner had

experienced the death of a parent, and they found that the death of a parent can change the adult child in fundamental ways. Some of the participants felt liberated and free of care giving duties to their dying parent, whereas others had begun to realize life is short and began to devote time for personal needs, such as health, achieving goals, or preparing for their own future death. Yet others felt like taking risks and “dancing” with wider variations of closeness and distance in the couple relationship than previously. Rosenblatt and Barner identified two main themes from the narrative reports of participants. One theme related to complications of support (e.g., the amount of support given or received and whether it was wanted or not), and the other centered on the time allowed to grieve (e.g., some partners expected the other to be “over” their grief by a certain time period). Some individuals were offered less support from their partner than they desired and this increased the emotional distance within the couple. Some wanted to be left alone for extended periods of time, and the accommodation of this wish by their partners was seen as supportive. Most participants reported that the support offered was appreciated and led to more opportunities for meaningful communication and feelings of closeness. Ten of the 18 couples reported that eventually, they became closer as they moved through their grief and felt that their relationship was enhanced due to the experience.

Grief Interventions

The following interventions may be of benefit to grieving individuals who are “stuck” within or having difficulties progressing through their grief. They may also be beneficial to those who are interested in learning how to better manage grief, for themselves or for their loved ones.

Narrative Therapy

According to Mahrer (1989), narrative therapy emerged out of the constructivist perspectives (e.g., Gergen, 1985), which hold that people construct meanings from their experiential world to fit with what is important or useful to them. White (1991) contended that some clients construct the meaning of their lives in interpretive stories. Similarly, Breunlin, Schwartz, and MacKue-Karrer (1997) suggested that every person involved in a situation has a subjective perspective on the “reality” of that situation, and life narratives are shaped and formed from this constructed reality. White (1991) argued that there are stories constructed either by oneself or with others (e.g., dominant society), which may be conflicting in reality, but are accepted by individuals as “truth” regardless. White further contended that the dominant society’s story has the power to diminish an individual’s personal freedom to choose what to believe, and can impact how an individual feels, reacts, and behaves with others (e.g., within his or her family, relationships, or society).

Narrative therapy rests on the assumption that people make “stories” of their life, in which they make meaningful connections among their life experiences. It is believed that in turn, the stories that individuals create influence their behaviours and emotions. For example, a story in which an individual is portrayed as “helpless” with cancer is more likely to feel sad or anxious (i.e., a depressed mood) and to behave in a passive manner (e.g., not want to get out of bed, have trouble concentrating). In contrast, a story that depicts individuals with control over their destiny may stimulate feelings of hope and inspiration, as well as behaviours that maintain these feelings (e.g., to engage in religious activities).

In narrative therapy, the therapist assumes a collaborative role, helping the client explore how and why they interpret their experiences the way they do (as reflected in their subjective, narrative reports). They do this by exploring the client's upbringing and cultural environment, which have consciously or unconsciously influenced them. These influences are reflected in what are called "thin conclusions," which are the narrow-minded, entrapping, negative endings to the problem stories that individuals accept uncritically (Morgan, 2002).

The primary goal of narrative therapy is to identify these "problem-saturated stories," which are dominating and oppressive, and to help clients develop alternative narratives through "re-authoring conversations" (White, 1991). These alternative stories show clients that their previous assumptions about themselves are not written in stone and can be changed, or re-authored, to new stories with better outcomes. Realities are never judged; rather, therapy is intended to show individuals how they construct their own realities and to open them to the possibility of constructing new personal realities (Morgan, 2002; White, 2005). Change takes place as individuals begin to live their new, more positive narrative roles.

White and Epston (1990) developed specific strategies to help individuals deconstruct the original narrative (i.e., the problem story). Techniques include the use of metaphors and "externalizing." Using metaphors allows clients to see their problem from a completely different view. For example, using the metaphor, "life as a novel," may allow a client to see how one underlying theme (i.e., the "thin conclusion") has influenced all the chapters in the novel of his or her life. Externalizing allows clients to separate themselves from the problem so they can view it more objectively. From this

standpoint, client and counsellor can “team up” to investigate the strengths and weaknesses of the problem.

Application to dying individuals and their families. Narrative therapy may help the terminally ill externalize their disease and gain a broader perspective on how they can deal with issues related to the illness. For example, terminally ill cancer patients can externalize the disease (the problem), in that they view it as a separate entity outside of the body, give it a name, and talk about the ways “it” affects them and others. From there, the therapist and client can identify ways in which “it” is not so overpowering (e.g., “when I pray”) and then investigate ways in which they can use this knowledge to better manage their problem (creating an alternative story). Narrative therapy may also be beneficial to the bereaved as an alternative way of dealing with the issues of loss and grief (Hedtke & Winslade, 2004).

Re-membering practices. One way to stay connected to the deceased is by engaging in Hedtke and Winslade’s (2004) re-membering practices, which are based on the narrative therapy approach. They are designed to teach the bereaved, through the metaphor of a personal membership club, that they can keep their loved one in their “club” by constructing stories that keep the deceased in their lives. Re-membering practices seem contrary to theories that hold that individuals can resolve their grief only by letting go and saying goodbye to the deceased. In contrast, re-membering practices encourage individuals to re-establish their relationship with the deceased on a different level, and keep the deceased “alive” in memories. For example, the therapist may ask the client what the deceased would want for them (“If your loved one could talk to you, what do you think they would say?” “Would your loved one want you to be so upset and sad

all the time?” “What do you think would make him (or her) proud of you?”). Asking these questions may instill a sense that the deceased still cares about the client and thereby provide comfort (Hedke & Winslade, 2004).

Grief Counselling

Lendrum and Syme's (2004) model of bereavement counselling focuses on the process and dynamics of the counselling relationship rather than specific tasks or stages of grieving. Lendrum and Syme identified three processes that help the bereaved navigate through their grief.

The first process focuses on the attitudes and core qualities of the counsellor. Lendrum and Syme (2004) argued that the bereavement counsellor should possess and offer clients the same attitudes and core qualities central to Rogers' humanistic psychotherapy (Rogers, 1992). Specifically, these attitudes are congruence (i.e., being genuine), unconditional positive regard (i.e., being non-judgmental), and empathy (i.e., understanding the client's feelings and experiences). A core assumption of humanistic therapy is that human beings have a natural desire to succeed in life. They have the resources within them to do so and will strive to flourish if conditions (in the environment) are right. Great emphasis is placed on the client-counsellor relationship. Counsellors behave in a non-directive manner and are genuinely interested in (and care about) the client and what the client has to share. Counsellors enter the subjective world of their clients by listening and reflecting back to them what they are hearing and experiencing. This not only verifies what the client is trying to convey; it also communicates that the counsellor is trying, as much as is possible, to understand the client's experience. This growth-promoting climate helps clients gain insight from their

experience(s) and helps to remove the blocks that are preventing them from thriving. It is assumed that bereaved clients who have sought out therapy are ready to talk about what they are feeling and experiencing, and Rogerian therapists allow clients to talk at length about their world. Lendrum and Syme (2004) argued that this atmosphere helps bereaved clients feel free to talk about their fears and feelings, safely experience their pain, and gain insight into and come to terms with their loss.

The second process in Lendrum and Symes' (2004) model focuses on the *expression* of the attitudes described above. It is considered important how the counsellor relays his or her responses to the client. Counsellors must be able convey empathy in both affective (feelings) and cognitive (thoughts) responses. For the bereaved, hearing that someone else (here, the therapist) truly "understands" what they are feeling and thinking may help relieve a sense of isolation. This trusting and honest relationship is considered the working alliance between client and counsellor, and it is the foundation from which healing and lasting change can begin (Hiebert, 2001).

In the third process, the counsellor attempts to identify specific defences that serve to protect the client (Lendrum & Syme, 2004). For example, some bereaved individuals maintain that they are not hurt or bothered by the loss in order to protect themselves from further pain, whereas others may fantasize about suicide as a way to achieve some relief from their pain. Counsellors inquire as to how the client expresses his or her grief, by, for example, asking if they cry over the loss or not. Those who report that they do not may be channeling their grief through other methods, such as anger, or ignoring their feelings altogether. However, it is important to recognize that some people, for various reasons, may not experience any strong emotions and this is accepted without

judgment. For those who do, counsellors help to facilitate an understanding that emotions are a natural response to loss, by engaging clients in various exercises (e.g., listening to one's own reactions, empathy exercises, identifying helpful and unhelpful responses). With the supportive underpinning of the working alliance, the counsellor and client can work together to identify such defences and bring new awareness of thoughts and behaviours.

Complicated Grief Counselling

Stroebe and Schut (1999) argued that earlier theories of grief did not sufficiently acknowledge the cognitive aspects of coping. Along these lines, Shear and colleagues (2005) developed a complicated grief treatment (CGT), which is a modification of interpersonal psychotherapy (IPT). According to Frank (1991, as cited in Shear et al., 2005) and O'Hara, Stuart, Gorman, and Wenzel (2000), IPT has been proven to be effective for treating depression. However, as Shear and colleagues (2005) pointed out, IPT does not address trauma or loss-related symptoms. Thus, Shear and colleagues (2005) blended IPT techniques with CBT techniques to address symptoms of depression (e.g., sadness, guilt, social withdrawal), trauma (e.g., disbelief, intrusive images, avoidance behaviours), and loss-specific distress (e.g., longing and yearning for the deceased).

As with IPT, CGT follows three phases of treatment: an introduction phase, a middle phase, and a termination phase. In the introduction phase, clients are educated about the normal and complicated aspects of grief, and learn about the dual process of adaptive coping in bereavement as described by Stroebe and Schut (1999). The client is also encouraged to identify new personal life goals.

In the middle phase, the bereaved “is desensitized to traumatic images of the deceased and thoughts about the death through an imagined conversation with the deceased and a retelling of the death scene” (Zhang et al., 2006, p. 1200). The conversation is conducted with the patient’s eyes closed, and the patient is instructed to imagine that he or she can speak to the deceased and the deceased can hear and respond. The patient is encouraged to talk with the deceased, and then to switch roles with the deceased and answer back (Shear et al., 2005). The “empty-chair” technique draws from Gestalt therapy and is designed to help clients access restricted feelings and resolve “unfinished business” (Perls, Hefferline, & Goodman, 1951, as cited in Paivio & Greenberg, 1995).

Shear and colleagues (2005) called the retelling of the death story “revisiting.” The patient’s recounting of his or her loss is audiotaped and played back, and any signs of distress are discussed with the therapist. The patient is also instructed to listen to the tape again at home during the following week. These exercises are focused on the loss-oriented aspects of grief, such as crying, yearning, and reminiscing with old photographs of the deceased (Stroebe & Shut, 1999). The dominant feeling in this process is “I miss him or her every day” (Matthews & Marwit, 2004).

Restoration-oriented focused exercises are designed so that the client imagines a state in which their grief is not so overwhelming. Examples include changing one’s identity (e.g., identifying one’s self as widow instead of spouse) and changing one’s role in life (e.g., leaning to cook or pay bills). Gradually, the client recognizes that, “I have to reorganize my life to continue on” (Matthews & Marwit, 2004).

Thus, during the middle phase, patients both confront and avoid the different issues of grieving as they work towards accepting the loss and adjusting to life without the deceased. Resolution begins when the client feels empowered rather than victimized, is able to make better choices that will lead to more favorable outcomes, and has a changed perception of himself or herself and the “other.” The termination phase focuses on review and assessment of the client’s progress, future plans, and preparation for the end of treatment (Shear et al., 2005; Zhang et al., 2006).

To compare the effectiveness of CGT with IPT for treating CG, Shear and colleagues (2005) conducted a randomized control trial of 83 mature adults (aged 18 to 85), who had met the criteria for CG, as defined by a score of at least 30 on the *Inventory of Complicated Grief* (ICG; Prigerson et al., 1995b). The ICG is a Likert-type scale, ranging from 1 = positive improvement to 7 = negative change, which identifies key features of CG. Participants were randomly assigned to one of two groups to receive either IPT or CGT, and each participant received 16 therapeutic treatments over a 16 - 20 week period. Pre- and post-treatment assessment included scales for depression, anxiety, CG, suicidality, and others. Change was assessed by (a) independent evaluation (by trained assistants blind to the treatment assignment), using the CGI, and (b) self-reported improvement of at least 20 points on the ICG (i.e., two standard deviations above baseline mean). Results showed that CGT is a more effective treatment over IPT for treating CG. CGT was also associated with having significantly faster response rates and faster time to response than IPT, meaning that those participants in the CGT group experienced positive relief of symptoms significantly faster than did those in the IPT group.

Hope Counselling

The reemergence of hope is a common goal in grief counselling (Cutcliffe, 1998). It is also a common motivator for individuals to seek help (Moore, 2005), and it can be key to grief resolution, just as hopelessness has been identified as a defining characteristic of complicated grief (CG) (Cutcliffe, 1998). What exactly *is* hope? Hope has been defined as “a confident expectation that a desire will be fulfilled” (Webster’s, 1988, p. 466). According to Cutcliffe and Grant (2001, as cited in Cutcliffe, 2004), hope is “multi-dimensional, dynamic, empowering, central to life, related to external help, related to caring, orientated towards the future, and highly personalized to each individual” (p.168). Jevne and Miller (1999, as cited in Moore, 2005) described hope as “...amazing. You can’t touch it but you can definitely feel it. You can’t physically see it by itself, but you can hold it and carry it. Hope doesn’t weigh anything but it can ground you and anchor you” (p. 101). How can hope and confidence reemerge when one is feeling hopeless?

Cutcliffe’s (2004, 2006a, 2006b) research and literature reviews on hope focused on whether grief counsellors are able to inspire hope in their clients, and if so, how it is done. For example, Cutcliffe (2004) conducted semi-structured interviews with 8 grief counsellors and 4 ex-clients who had undergone grief counselling, to examine the process variables that may contribute to the growth of hope. Cutcliffe concluded that counsellors do inspire hope in their clients, through an integrated process that included one core variable (i.e., the implicit projection of hope and hopefulness) and three subcore variables (i.e., forging the connection and relationship; facilitating a cathartic release; and experiencing a healthy (good) ending).

According to Cutcliffe (2006a; 2006b), hope inspiration in grief counselling is a three-phase process that begins with establishing a strong and trusting relationship between client and counsellor. In the first phase, called *forging the connection and relationship*, the counsellor creates an atmosphere of warmth, caring, and safety for clients so that they might experience a caring, human-human connection. By projecting a Rogerian presence, counsellors allow clients to test the strength and trust of the relationship by encouraging them to express their emotions freely.

The counsellor offers commitment by conveying that he or she can tolerate anything the client discloses, and thus, clients come to understand that they can trust in this new relationship, and may be able to rediscover trust towards others, too (Cutcliffe, 2006a). As well, the counsellor gently counters projections of hopelessness. As clients observe that their disclosures do not harm the counsellor or cause the counsellor to abandon them, hope emerges (Cutcliffe, 2006a).

As the process shifts to the second phase, *facilitating a cathartic release*, the client intermittently tests the security and safety of the relationship while progressing towards a healthy ending to grieving. According to Cutcliffe (2006b), the trust and connection within the therapeutic relationship works like a safety net as clients begin to release painful emotions and thoughts. As a result, clients feel a sense of relief and lightness, and hope for a future that is pain-free, or at least, less heavy with emotion. They feel free to reflect on their loss and address issues of hopelessness that may be preventing a healthy resolution to their grieving.

Providing unconditional and sustained support to clients is accomplished by nurturing the therapeutic connection at the onset, continuing to provide a safe and caring

therapeutic atmosphere, and helping the client identify additional sources of support available to them (Cutcliffe, 2004, 2006b). The trusting therapeutic relationship is also necessary for clients to feel free to talk about the deceased without feeling judged or worried that they will cause harm to others (Cutcliffe, 2006b).

Sometimes, words are unnecessary and silent moments also allow clients and counsellors to “track into their emotional self, at a deeper level” (Cutcliffe, 2006b, p. 607), and offer clients the opportunity to release painful emotions (e.g., through tears). Moreover, a therapeutic touch (e.g., holding the client’s hand, touching the client’s shoulder) may be effective in conveying messages of caring and understanding. However, if used inappropriately, therapeutic touch can have adverse effects and may negatively impact therapy (Cutcliffe, 2006b).

Cutcliffe’s (1998, 2004) underlying message is that hope, like the feelings of connectedness within a strong, trusting relationship, can be implicitly communicated by the counsellor. The counsellor’s task is to avoid colluding with the client’s sense of hopelessness and denial, and refuse to succumb to hopelessness. This act of resistance in the therapist instills hope in the client (Cutcliffe, 2006b).

In the third phase, *experiencing a healthy (good) ending*, clients realize through increasing self-awareness that their present feelings of hopelessness can eventually turn around and that their grief is not a fixed state. They also learn that grieving is a process of experiential learning and that they are continually evolving as a result. Thus, they realize the potential for growth in bereavement (Cutcliffe, 2006b).

In this phase, clients also learn to reflect upon, identify, and avoid repeating previously learned, unproductive reactions to a loss, which may have contributed to their

feelings of hopelessness (Cutcliffe, 2006b). Clients are supported in accomplishing any tasks of bereavement they deem necessary to help them move towards a healthy end to their bereavement. This encouragement helps clients feel they have some control over their subjective situation, and this, in turn, can inspire hope.

Cutcliffe (2006b) highlighted the need for counsellors to be flexible in negotiating termination dates for therapy. For some, ending therapy may be viewed as another loss. Thus, giving clients some power to determine the end of therapy may help them “recognize and accept they have moved on, have even grown....[and] when clients can reflect on the progress they have made during the therapy, they gain a sense of hope and become more hopeful” (p. 609).

Cutcliffe (1998) observed that many hope-inspiring strategies are implicit and unobtrusive, and that even the “presence of another human being who demonstrates acceptance, tolerance and understanding [inspires] hope” (p. 755). Therefore, hope inspiration may actually be a by-product of the trusting relationship (Cutcliffe, 2006a).

Cutcliffe (2004, 2006a) also noticed that progression through each phase is not necessarily linear or unidirectional, and that there are sometimes cyclic movements within them. For example, some clients seem to test the strength and trust of the relationship throughout all three phases of the bereavement experience. For others, the fear of experiencing another loss seems to prevent them from establishing new relationships.

Retrieving hope. Moore (2005) proposed the concept of a “hope kit” as a strategy to inspire or boost hope. The term refers to a small collection of personal items that stimulate hope of attaining a goal or dream; it is like a personal “insurance policy” to

draw from in times when hope is depleted and needs recharging. Clients are encouraged to assemble items that are personally meaningful and which represent hope for them. For example, Moore keeps a walking stick in her hope kit to inspire dreams of a future mountain-climbing trip. She suffered a broken back and reconstructive surgery in the past, and on days when she has pain and doubts about her future health and abilities, the walking stick helps to refocus her thoughts towards future possibilities. Possibility is a dimension of hope, which is critical when looking towards the future.

Grief Rituals

Ritual has been defined as “a traditional method of conducting and performing an act of worship or other solemn ceremony” (Webster’s, 1988, p. 859). Castle and Phillips (2003) defined a ritual as:

any activity – sacred or secular, public or private, formal or informal, traditional or newly created, scripted or improvised, communal or solitary, prescribed or self designed, repeated or one-time only – that includes the symbolic expression of a combination of emotion, thoughts, and/or spiritual beliefs of the participant(s) and that has special meaning for the participant(s). (p. 43)

The funeral ritual provides the bereaved with some structure during the fast-paced, chaotic period after a loved one has died. The gathering of friends and family at the funeral service helps to reduce feelings of isolation, provide social support, and encourage the bereaved to accept the reality of the death (Castle & Phillips, 2003). After the funeral, and particularly in the period when social support declines, at around

6 months (McBride & Simms, 2001), rituals may help the bereaved cope, reduce anxiety, and to include others in sharing the loss (Castle & Phillips, 2003).

The use of physical symbolic items (e.g., photographs or possessions of the deceased) or nonphysical items (e.g., music, poetry, prayers) may be helpful for expressing deep emotional feelings (Castle & Phillips, 2003). Talking to a sensed presence of the deceased may encourage a continued emotional connection and a new relationship with the deceased (Bennett & Bennett, 2000).

Shared reminiscing (Rosenblatt & Elde, 1990) (i.e., sharing memories of the deceased with family and friends), as well as eating foods, visiting places, and doing things that were important to the deceased, are also considered rituals that help soothe the pain of loss. They are just some examples of “hidden” rituals that the bereaved perform, all of which may facilitate the healing process (Rosenblatt & Elde, 1990).

Memorializing

Creating memorials on the Internet may provide the bereaved with a sense of connection to others who are also grieving. Through memorialization, the bereaved have an opportunity to continue their relationship with the departed for as long as they need or desire it. “Web cemeteries,” which are virtual web sites with information about the deceased, offers the bereaved both a private place to mourn and a public place to honor their lost loved ones (Moss, 2004). For example, the *Virtual Memorial Garden* (VMG) is a site in which the obituary, along with photos of the deceased, are displayed, and one can leave a message in the guest book or order virtual flowers to be left on the site. The VMG web site is free of charge, where anyone (including pets) can be remembered (Marshall, n.d.).

Donating a bench to be situated in a favorite park of the deceased is another popular way of memorializing a deceased loved one, as is planting a tree (*Memorial Park Bench & Tree Program*, n.d.). Several funeral homes in Calgary, Alberta offer this type of memorialization in their funeral packages.

Lastly, individuals who choose to donate body parts are memorialized at the Garden of Life Angel Tree, located in the Devonian Gardens in Calgary, Alberta. A photograph, along with a brief eulogy, is hung from the branches, and is a beautiful and humbling sight to see as one strolls through the picturesque gardens (CHR, 2007; Lions Eye Bank, 2007).

CONCLUSION

Across historical time, the mores surrounding death have changed dramatically. People in Western cultures used to die at home, and family, friends, and clergy were responsible for their care. Over time, the location of death has transitioned to the hospital and medical professionals have assumed primary responsibility for the dying. Thus today, death is managed from a biomedical perspective, which tends often to eclipse the psychosocial and spiritual aspects of the experience.

We all want to experience a good death – for ourselves and for our loved ones, but at this time, this desire appears to be a hope rather than standard practice in the medical field. However, palliative medicine is becoming increasingly recognized and requested by patients, and the voices of the dying are now being heard. Palliative medicine offers a different kind of healing. When medical science can no longer cure the illness, palliative medicine takes over and offers care and understanding to dying individuals and their loved ones based on their unique needs and wants. When patients are identified as needing palliative care, the average time left to live is usually under three months, and the average stay in the AGAPE Hospice in Calgary, Alberta is 13 days (J. Lemke Clow, personal communication, October 2, 2007). Thus, there is no time to waste in helping terminal patients and their families to experience as “good” a death as possible. Patients and family members need to be quickly assessed as to their needs and offered appropriate interventions to help them on their journey towards whatever it is they consider a good death.

Being able to recognize and understand the psychosocial phases of living with a terminal illness and the bereavement process can help the dying and their caregivers to be

prepared for what is to come as the illness progresses, as well as what one can expect after the loss. Some of the theoretically driven interventions in this review can be self-taught and administered, which can help people regain a sense of control of their situation in life and death. These interventions promote autonomy which patients themselves indicate is vitally important to them.

The completion of this project has facilitated my learning in several ways. In asking the questions that guided this review (e.g., What is a good death? How can dying individuals achieve a good death? How can the experience of loved ones be enhanced?), I discovered meaningful information that will assist me with future clients who have been diagnosed with a terminal illness or who are experiencing grief. In particular, I will be able to validate the normalcy of their symptoms and reactions, and of most importance, I will be attuned as to what symptoms and reactions are not typical and in a position to offer appropriate support and help. However, I am cognizant of the fact that the dominant notion of what's "typical" is based on research with a primarily mature, white, North American, middle-class population.

I also learned a great deal about myself as I reviewed articles about the grieving process, and as I moved through my own grief. At times early in my bereavement, I felt that my pain was unbearable, but I was hopeful for the future as the literature repeatedly indicated that the intensity and depth of my pain should lessen (typically) at around 6 months postloss. I held on to those assertions like a life-preserver, and I did, in fact, begin to notice that my symptoms and the severity of suffering began to wane at about this time. Whether this outcome can be attributed to "the power of suggestion" or not can be debated; however, I was grateful when the specified time arrived and afforded me some

alleviation of my pain. I am uncertain as to how my grief would have progressed (in intensity and in duration) had I not been educated. Due to this experience, I believe that I will be able to competently offer grief counselling to future clients in my career. In bereavement, there is no “right” or “wrong” way to grieve. This notion helps to dispel the worry that one is not grieving “normally” or “properly” and may lessen the weight of suffering. Communication and support are crucial as grieving individuals move through their grief, and this process takes time. How much time is needed will depend on the individual and his or her circumstances.

Having completed this project, I also believe that I will be able to comfortably discuss delicate issues in counselling that many find difficult to tackle. For example, I have a better understanding of why some individuals with terminal illness desire a hastened death. I also know (from personal experience and from my reading) how difficult it is to watch a loved one suffering, and to secretly wish for an end to their pain. Even though these distasteful thoughts are in the best interest of the loved one, the guilt experienced is enormous. Having an understanding, compassionate ear to listen to these concerns will be beneficial to clients in similar situations.

We strive for quality in living and we should also strive for quality in dying. It is my hope that future students or researchers will extend the information compiled in this review, and eventually produce a handbook that can be accessed by the dying, their family members, and others involved in palliative and bereavement care.

Facing mortality does not have to be a fearful, completely uncontrollable experience. Death will come, but if we are prepared, we can help ourselves and others to leave this world with dignity and peace.

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APPENDIX A

Factors Important At The End Of Life

The following are 26 factors, listed in order of importance, that dying patients consider are very important at the end of life:

1. To be kept clean.
2. To name a decision maker.
3. To have a nurse with whom one feels comfortable.
4. To know what to expect about one's physical condition.
5. To have someone who will listen.
6. To maintain one's dignity.
7. To trust in the physicians.
8. To have financial affairs in order.
9. To be free of pain.
10. To maintain a sense of humor.
11. To say goodbye to important people.
12. To be free of shortness of breath.
13. To be free of anxiety.
14. To have a physician with whom one can discuss fears.
15. To have a physician who knows one as a whole person.
16. To resolve unfinished business.
17. To have physical touch.
18. To know that the physician is comfortable talking about death and dying.
19. To share time with close friends.

20. To believe that family is prepared for one's death.
21. To feel prepared to die.
22. To experience the presence of family.
23. To have treatment preferences in writing.
24. To not die alone.
25. To remember personal accomplishments.
26. To receive care from a personal physician.

Note. From "Factors considered important at the end of life by patients, family, physicians, and other care providers," by K. E. Steinhauser, N. A. Christakis, E. C. Clipp, M. McNeilly, L. McIntyre, & J.A. Tulsky, 2000, *Journal of American Medical Association*, 284, pp. 2476-2482. Copyright 2000 by the American Medical Association. All rights reserved. Adapted with permission.

APPENDIX B

Psychosocial Interventions

The following are professionally perceived effective psychosocial interventions:

<u>Category</u>	<u>Psychosocial Interventions</u>
Meaning-centered approach:	Exploring patient life values
	Life review interviews
	Cognitive restructuring
	Enhancing creativity
	Establishing realistic short-term goals
	Insight-directive psychotherapy
Providing comfortable environments:	Art therapy
	Relaxation
	Alleviating physical symptoms
	Strengthening social support
Supportive-expressive approach:	Acceptance and respect of patient
	Authentically listening
	Paying attention to the patient
	Reassuring normality of patient's feelings
	Encouraging patient's expression
Religious Approach:	Religious care
	Praying
Education and coping skill training:	Strengthening self-efficacy
	Providing realistic information about illness

Being: Clarifying past psychological history
Enhancing problem solving
Sharing time
Touch

Note. From “Professionally Perceived Effectiveness of Psychosocial Interventions For Existential Suffering of Terminally Ill Cancer Patients,” by K. Hirai, T. Morita, & T. Kashiwagi, 2003, *Palliative Medicine*, 17, 688-694. Copyright 2003 by Arnold Publishing. Adapted with permission.

APPENDIX C

SELF-HYPNOSIS: The Basic Procedure of Becoming Relaxed

1. Make yourself comfortable.
2. Tilt your eyes above their normal line of vision so that you feel a slight degree of eye strain. Keep your eyes fixed in this position while staring at some spot. Now take five deep abdominal breaths (e.g., fill you abdomen with air so it visibly expands), **very slowly and rhythmically**. Do not hold the first four breaths.
3. Inhale the fifth breath extra deep, and while holding it, count backwards mentally “5,4,3,2,1.”
4. When you get down to “1,” exhale and close your eyes simultaneously, and drop into hypnosis.
5. Focus your attention momentarily on each muscle group in your body, beginning with your head and working down to your toes. Allow your entire body to become physically relaxed. If desired, you can also give yourself a few global suggestions of relaxation, such as “*I feel a warmth throughout my body,*” or “*I feel so heavy that I can hardly move,*” or “*I feel myself going deeper.*”
6. Allow yourself to relax mentally by counting backwards slowly from 10-to-1.
7. Stay in hypnosis for at least 3 or 4 minutes. You will probably find that 10-to-20 minutes is better when you are first learning this technique. Until you begin using Part 2 of self-hypnosis, do one o f the following while in self-hypnosis:
 - (A) Firstly, you can let your mind be completely free of all thoughts, distractions, and worries. Sometimes you will find that a few thoughts enter your mind rather automatically, or possibly your imagination will

become more active. Either way, it is totally acceptable so long as it occurs without you making any effort to make it happen.

(B) Secondly, you can begin counting backwards mentally from a predetermined number at the rate of one number for each exhalation. As you breathe outwards, you count the next number down in sequence.

8. When you wish to awaken tell yourself that you will count to five, and that at the count of five, you will come out of self-hypnosis feeling refreshed, relaxed, and confident. Then awaken yourself by counting to five mentally, and say “AWAKE!” to yourself.

Note. From “*Self hypnosis: Part 1: Part 2,*” by K. Alderson, n.d., unpublished manuscript. Reprinted with permission.

APPENDIX D

SELF-HYPNOSIS: Self-Change Techniques

Using Verbal Suggestions with Self-Hypnosis

1. Write a positively-worded suggestion on a piece of paper or cardboard. The suggestion should be a once-sentence statement that conveys the intent of your goal. For example, if you wanted to become a calmer individual, you would not use the suggestion, “*I will try to become less **tense** each day*” for two reasons. Firstly, the word try implies the possibility of failure to your subconscious mind, and secondly the work tense may actually increase your tension. Instead, find a more positive word that means its direct opposite. For example, a positive suggestion is “*I will become **calmer** each day.*” The word calm suggests the desired outcome.
2. Read the suggestion to yourself five times before entering self-hypnosis. The suggestion should be read slowly, meaningfully, and reflectively so that it becomes the most important thought entering your mind.
3. Place yourself in self-hypnosis and remain there for at least 3 or 4 minutes.
4. During the 3 or 4 minutes (or longer), you will find that the words in the suggestion begin to enter your mind in an automatic or semi-automatic fashion, although not necessarily in their correct sequence. If the words are not forthcoming on their own, use as little effort as possible to bring the key words of your suggestion into your mind.

5. Awaken yourself in the usual manner.

Note. From “*Self hypnosis: Part 1: Part 2,*” by K. Alderson, n.d., unpublished manuscript. Reprinted with permission.

APPENDIX E

Using Visual Imagery with Self-Hypnosis

1. Make a list of the various images that you plan to visualize while in self-hypnosis to help you accomplish your goal. In essence, each image selected should reflect the outcome of your goal. For example, if you want to quit smoking, your visual images may include seeing yourself exercising without shortness of breath, taking a holiday with the money you have saved from not smoking, and enjoying your morning coffee without a cigarette. Each image represents the result of being successful at your goal.
2. After you have your list of images prepared, place yourself into self-hypnosis.
3. Begin to imagine as vividly as you can, each of your images. Make each image as real as possible and create a feeling of accomplishment toward each image.
4. After at least 3 or 4 minutes of visualization, awaken yourself in the usual manner.

Note. From “*Self hypnosis: Part 1: Part 2,*” by K. Alderson, n.d., unpublished manuscript. Reprinted with permission.

APPENDIX F

Progressive Muscle Relaxation

In this method of relaxation we are trying to get you completely relaxed, into a deep state of relaxation without any movement, without any tension, any stiffness and almost without any feeling, so you mustn't be frightened of letting go and you must try to avoid fidgeting.

Now we just deal with each part of the body in turn and we start off with your arms. Both your arms from your shoulders right down to your fingers, try and let both arms just hang loosely from the shoulders and rest on the chair or the bed or whatever, and you think first of all about your fingers, that the fingers aren't stiff or tense, that your hands are relaxed, your wrists are quite loose, your lower arms relaxed, your elbow joints quite loose, upper arms relaxed and your shoulder joints quite loose, so that your arms are hanging quite loosely and resting quite heavily on the chair or the bed.

Your arms are as relaxed as you can get them, now that does not mean to say that they are completely relaxed — you have to learn to relax. As long as you are quite confident that you are not moving them and there is no stiffness then you will probably become more and more relaxed as time goes on. This is you learning to relax, both your arms are as relaxed as you can get them at this stage and it doesn't matter how much, how relaxed that is as long as they are as relaxed as you can get them. They should feel quite heavy, quite loose, quite limp, almost as if they didn't belong to you — switched off, pressing down quite heavily on the bed of the chair. Now leaving your arms as relaxed as they are move on to your legs. That's both legs from your hip joints right down to your toes, we start off with your toes. There will be no stiffness, feet should be relaxed, your ankles loose, your lower legs relaxed, the knee joints relaxed, your upper legs relaxed, your hip joints should feel quite loose, so that both your legs like your arms are loose, limp and heavy as relaxed as you can get them at this stage. No movement no stiffness, not much tension, completely switched off, almost as if they didn't belong to you, your arms and your legs loose, limp and heavy just like lumps of lead, completely switched off

Now we move on to your body — to your stomach muscles. Just let your stomach muscles relax and sag. Next your back muscles — its very hard to tell if back muscles are relaxed so don't worry too much about them. Your should muscles you can certainly feel tense but as long as you are not tense in your shoulders, holding them very stiff then they probably will relax as well as you begin to get more and more relaxed.

And now we come to the breathing and breathing is very important. Breathing is the most important of the lot, your breathing should be nice and smooth, it doesn't matter how fast or how slow or how deep or how shallow, nice smooth breathing is a sign of relaxation because you have to relax to breathe normally. If you are tense then you can't breathe normally and you have to have an extra breathe or an extra deep breathe every now and again, but if your chest muscles are relaxed then you can breathe nice and smoothly.

Keeping your mouth a little bit open can help, this can help to dry up the saliva, you don't have to keep swallowing, also if you breathe through your mouth you can use your stomach muscles to breathe rather than your chest muscles and that's usually a more relaxing kind of breathing. you feel your stomach rising and falling as you breathe in and out through your mouth. Now because you normally relax when you are breathing out you can use this breathing out to get yourself more relaxed, so as you breathe out really let go, just let the air come out almost in a sigh. Relax, relax and really letting go every time you breathe out, feel yourself sinking deeper and deeper into the chair, more and more switched off. You can feel the tension flowing out through your fingers and out through your legs and out with your breath and really relax and let go. You can often use this breathing to help you to relax quickly. Breathe out, really letting go and don't be frightened to let go —its perfectly safe. Keep your breathing nice and smooth and now we will pass back to your shoulder muscles and make sure that they are still relaxed. Make your neck muscles as relaxed as you can get them, let your throat relax, your jaw slightly open, your tongue relaxed, your cheeks, eyes, eye lids and forehead, your whole face should be quite expressionless, because your face is switched off too — really letting go, no tension, no stiffness, no expression on your face, just as when you are asleep, when you are asleep you are deeply relaxed and you are trying to achieve the same depth of relaxation while you are still awake. You are leaning to give all your muscles a good rest, how to feel that you are switched off, that you are not on edge because that is one of the great benefits of relaxation.

Now we have been through all of the muscles once and you may feel a bit more relaxed than you were but don't worry too much about just how relaxed you are, what you do in the course of 15-20 minutes is just go through that again and again, just getting more relaxed, because you go back to muscles you may find that they have tensed up again because that is their habit, habit means what they do when you are not thinking, If they have tensed up again you have to relax them consciously once more or you may find that you can get a bit more relaxed than you could previously because the rest of you is more relaxed and don't worry too much if you have missed anything out, if you are really relaxing even if you have missed out a muscle it will relax anyway, it's quite safe to relax a nice natural thing to do, you do it every night when you are asleep.

So now we go through the muscles again, that's both your arms, fingers, hands, wrists, lower arms, elbows, upper arms, shoulder joints, both arms loose, limp and heavy, no movement, no stiffness, no tension. You may detect a tingling in your fingers and that's a good sign, a warm tingling is a sign that can happen in other parts of your body as you get more and more relaxed, its not the same as pins and needles, it's a very safe things a nice warm tingling, keep your arms relaxed.

Now we move on to your legs again. You probably will find that they have tensed up particularly if you are sitting in a chair, so again think about your toes, feet, ankles, lower legs, knees, upper legs, hips, your legs also are now relaxed as relaxed as you can get them and moving on — start muscles relaxed, back muscles not too tense, breathing nice and smoothly through your mouth and using your stomach muscles. Don't be frightened of letting go, don't be frightened of drifting away, its perfectly safe, you are always very

safe when you are relaxed, your body is at rest, therefore no great strain is being put on your body or being put on your heart, your heart is more at rest when you are relaxed.

Now we move on to your shoulders again, your neck and throat, tongue, jaw, cheeks, eyes and eye lids, forehead, deeply relaxed, deeply relaxed. Once you feel that you are quite good at relaxing when you do the muscles and you feel that you are really quite relaxed then memorize what they feel like, memorize what your arms feel like when they are relaxed, what your face feels like when it is relaxed, if you memorize then its easy to detect when you are tense and then you can correct it by relaxing and by going through this tape you have been learning how to relax but the important thing is to use this relaxation at other times. During the day just try and become a more relaxed kind of person no matter what you are doing whether its sitting watching television, whether its moving around the house, whether its out for a walk, try to do it in a relaxed kind of way so your arms are relaxed, your face is relaxed and you just become a more relaxed kind of person.

Note. From “Relaxation Techniques,” by E. Jacobson, n.d.,

http://www.berwickheartsupport.co.uk/html/progressive_relaxation_graeme.HTM.

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Additional Web sites:

<http://www.hypnos.co.uk/hypnomag/jacobson.htm>

<http://www.guidetopsychology.com/pmr.htm>

<http://www.hypnos.co.uk/hypnomag/jacobson.htm>

<http://www.mayoclinic.com/health/relaxation-technique/SR00007>

<http://webpace.ship.edu/cgboer/musclerelaxation.html>

<http://www.medicinenet.com/script/main/art.asp?articlekey=47281>

APPENDIX G

Relaxed Breathing

This relaxation technique does not need you to tense or move your muscles. It is done lying down. First you have to concentrate on your breathing.

After three or four minutes of concentration on your breathing, move your attention to your toes. Don't move these, just think about how they feel. Don't worry if you don't feel anything at all. If you find any tension there, let it go as you breathe out.

After a few moments of your concentration on your toes, move your attention to the bottoms of your feet. Again, don't move, just concentrate on any sensations you have. Let go of any tension you may find as you breathe out. Next concentrate on the top of your feet and your ankles. After a few more moment, bring your attention to your lower legs.

Continue this process, shifting your attention every few moments to another part of your body, working slowly upwards towards your head. If you find tension, let it go as you breathe out. If your mind starts to wander, just bring your attention to the feelings in your body and your breathing.

This technique can also be used to help you get to sleep because it helps to clear your mind of any worries or distracting thoughts. The key is to give your full attention to scanning your body for tension and releasing it.

Exercise 1:

The Stimulating Breath (also called the Bellows Breath)

The Stimulating Breath is adapted form a yogic breathing technique. Its aim is to raise vital energy and increase alertness.

- Inhale and exhale rapidly through your nose, keeping your mouth closed but relaxed. Your breaths in and out should be equal in duration, but as short as possible. This is a noisy breathing exercise.
- Try for three in-and-out breath cycles per second. This produces a quick movement of the diaphragm, suggesting a bellows. Breathe normally after each cycle.
- Do not do for more than 15 seconds on your first try. Each time you practice the Stimulating Breath, you can increase your time by five seconds or so, until you reach a full minute.

If done properly, you may feel invigorated, comparable to the heightened awareness you feel after a good workout. You should feel the effort at the back of the neck, the

diaphragm, the chest and the abdomen. Try this breathing exercise the next time you need an energy boost and feel yourself reaching for a cup of coffee.

Exercise 2: The 4-7-8 (or Relaxing Breath) Exercise

This exercise is utterly simple, takes almost no time, requires no equipment and can be done anywhere. Although you can do the exercise in any position, sit with your back straight while learning the exercise. Place the tip of your tongue against the ridge of tissue just behind your upper front teeth, and keep it there through the entire exercise. You will be exhaling through your mouth around your tongue; try pursing your lips slightly if this seems awkward.

- Exhale completely through your mouth, making a whoosh sound.
- Close your mouth and inhale quietly through your nose to a mental count of **four**.
- Hold your breath for a count of **seven**.
- Exhale completely through your mouth, making a whoosh sound to a count of **eight**.
- This is one breath. Now inhale again and repeat the cycle three more times for a total of four breaths.

Note that you always inhale quietly through your nose and exhale audibly through your mouth. The tip of your tongue stays in position the whole time. Exhalation takes twice as long as inhalation. The absolute time you spend on each phase is not important; the ratio of 4:7:8 is important. If you have trouble holding your breath, speed the exercise up but keep to the ratio of 4:7:8 for the three phases. With practice you can slow it all down and get used to inhaling and exhaling more and more deeply.

This exercise is a natural tranquilizer for the nervous system. Unlike tranquilizing drugs, which are often effective when you first take them but then lose their power over time, this exercise is subtle when you first try it but gains in power with repetition and practice. Do it at least twice a day. You cannot do it too frequently. Do not do more than four breaths at one time for the first month of practice. Later, if you wish, you can extend it to eight breaths. If you feel a little lightheaded when you first breathe this way, do not be concerned; it will pass.

Once you develop this technique by practicing it every day, it will be a very useful tool that you will always have with you. Use it whenever anything upsetting happens - before you react. Use it whenever you are aware of internal tension. Use it to help you fall asleep. This exercise cannot be recommended too highly. Everyone can benefit from it.

Exercise 3: Breath Counting

If you want to get a feel for this challenging work, try your hand at breath counting, a deceptively simple technique much used in Zen practice.

Sit in a comfortable position with the spine straight and head inclined slightly forward. Gently close your eyes and take a few deep breaths. Then let the breath come naturally without trying to influence it. Ideally it will be quiet and slow, but depth and rhythm may vary.

- To begin the exercise, count "one" to yourself as you exhale.
- The next time you exhale, count "two," and so on up to "five."
- Then begin a new cycle, counting "one" on the next exhalation.

Never count higher than "five," and count only when you exhale. You will know your attention has wandered when you find yourself up to "eight," "12," even "19."

Try to do 10 minutes of this form of meditation.

Note. From "The art and science of breathing," by A. Weil , 2008,

<http://www.drweil.com/drw/u/ART00521/three-breathing-exercises>. Copyright 2008 by

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Additional web sites

http://www.holisticonline.com/Remedies/Anxiety/anx_breathing.htm

APPENDIX H

Death Preparation Meditation

You're not your body, you're not your mind, you're not your emotions. What you are, who you are, who your Real Self is, is the consciousness that can witness your physical, mental, and emotional reactivity and activity. It is your birthright to know this consciousness and recognize its energy, infiniteness, and eternal nature as your own. When you drop this body, you will not be doing anything new or different. Every night you go to sleep in your physical body and awaken to and use your astral/dream body. That already accounts for 1/3 of your life that you don't spend interacting with your puss, urine, feces, mucous, phlegm container. Even during the other 16 hours of the day, we are rarely in touch with or body.

Virtually all of our time is spent daydreaming about fulfilling our desires and fantasies or regretting what we have done to others or what they have done to us. "I would of, should of, could of" disease runs rampant and takes up huge chunks of our life. We rarely are aware of what our body is experiencing and even when we are it is usually only one sensation at a time. If we're listening to something, for instance, we are totally unaware of what our body is seeing, touching, tasting, or smelling. Thus, in a way, most of the time, 4/5 of our body is dead to us. Looking at the situation scientifically, we are a collection of cells made up of molecular compositions that are in constant flux. There is never a second that our atomic structure isn't changing. Every moment our molecules are different, our cells are different, our body is different. In this perspective, our body dies and is reborn every second. In reality, every atom in your body has changed from the time you started reading this until this very moment. And in the Now, you are again completely different. Similarly, when the inevitable moment comes when the energy of life leaves your body forever, the cellular, molecular, atomic, and subatomic structure of your body will simply continue doing what it always has. Your cellular composition will change into other molecular groupings. Atomic and sub-atomic processes will break down your molecules into components that will merge with other molecules and life will go on.

When you die, what once were the cells that made up your flesh and bones will go into the earth and merge with the soil where they may be joined with other molecules that grow in the earth, like grass, get eaten by cows, which get eaten by people. They then get diffused as food into the cell structure of the person who ate them. If a body gets cremated, the particles are dispersed into the air and could be inhaled into someone's lungs and merge with that person's cell structure. If a body is buried at sea, its parts could be eaten by a fish that gets eaten by a person and becomes an integral part of their body. The cell absorption process merges with bodies and life continues. This has been going on for millions of years. It has been said that with every inhalation, we breathe in atoms that once were parts of everyone who has ever lived.

Please meditate on these obvious facts of life and cease and desist your illusion of being your body. It is simply an ever-changing collection of atoms that will continue changing forever, whether there is a living energy in it or not. You are not your mind or emotions either. They keep constantly changing, are inconsistent, and yet you know intuitively, in your gut, that you are constant. When you are awake or dreaming, your

thoughts and feelings fluctuate between good and bad, happy and sad, clear and cloudy, calm and distressed, depending on the internal or external things stimulating you at the time.

What you are is the consciousness that can and does witness the activity and changes of your mind, body, and emotions. It is not that which comments, judges, or compares. That is a function of your mind called your intellect. Rather, it is that which witnesses the commentary, judgments, and comparisons in silence that you are when you say, "I AM." This consciousness is within everything, everywhere witnessing everything, everywhere. When you stop identifying with your body, mind, and emotions, as happens at death, you gain the opportunity to tune into the infinite consciousness and witness all the permutations of life that have eluded you when you limited your experience to just those things experienced via the five senses of the human body and the finite intellectualizations and emotionality that go with them. Just as a chick gains new freedom when it emerges from its shell, you will enjoy an exquisite, infinite release from bondage when you drop your attachment to your body. Like a butterfly freed from its cocoon, you will soar into the stream of universal consciousness. Once free from the limitations of experiencing life with only 5 senses, you will never want to go back. And yet you will have to until the time comes when you have evolved beyond the misidentification of your self as apart from the rest of the universe instead of as a part of it. To help you achieve this merging and emerging, you have to stop fearing the passing of your body and prepare to do it calmly with a willingness to face the next phase of your evolution as the silent Witness that in fact you are and have always been. To help accomplish this, there is a specific meditation technique that allows you to practice what it will be like to die. It allows your real self, your Witness, to become more apparent to you at the same time as you become aware of that which will occur at the time of death.

It is very easy to do this technique and yet very few meditations have such a great potential for learning and making a profound evolution in your conquering of the fear of death. Simply inhale slowly and deeply, as slow and deep as you can. Hold your breath as long as you can. Then, exhale as slowly and fully as is comfortable and then refrain from inhaling again for as long as you can. Repeat this 12 times, rest and do 3 to 11 more sets of this inhale, hold, exhale, hold rhythm. You may find it quite a strange feeling, even alarming, when you first try to have no air in your lungs, but you will soon find that the more relaxed you stay during that time, the easier it becomes and the more comfortable you become. As a matter of fact, this may become the most influential technique you ever do for self-knowledge. You can learn greatly about the way our body, mind, and emotions are reacting and causing you to react to the fear of death. You will gain first-hand knowledge of your real identity as the Witness that is transcendent of the body, mind and emotions and gain the kind of faith that only the surety that first-hand experience can provide. There really is going to be a time that will come when you exhale and never inhale in this body again.

Virtually every religion has prayers and rituals for the time of death and just after, that are intended to bring a calming to the one going through the experience. This meditation technique will get you used to the state and you will be calm and collected at that precise precious time you die forever to the attachment to this body. You can then collect your heavenly reward and truly live happily ever after.

Note. From “Death and How to Prepare For It,” by B. Rose, 2006,

<http://www.meditationsociety.com/week7.html>. Copyright 1997 - 2006 by Meditation

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APPENDIX I

Guided Imagery

This script can be read slowly a tape recorder in your normal voice. Pause periodically so that when you listen to the tape, you will have time to absorb the instructions.

PROCEDURE FOR LISTENING TO GUIDED IMAGERY

Allot roughly twenty minutes, twice a day
 Sit or lie quietly where you can be alone and quiet for that period of time.
 Play the tape. It contains all the directions.
 Make a conscious effort to follow the directions on the tape.

SCRIPT

This is going to be a time of complete relaxation...a conscious effort to relax as completely as possible. Get into as comfortable a position as you can, and close your eyes. For the next couple minutes, just concentrate on your breathing. To the best of your ability, see your lungs, see how they feel, consciously see how they feel while they're completely expanded, and see how they feel after you exhale. Be aware that there's no right way and no wrong way to do what you're doing now...that whatever results you get are perfect results, and that if all you do is relax, that's wonderful. This is not a time to be worrying about any of the things that are happening in your day-to-day life. This is a time only for you, and you can let it all hang out. For this very short period of time, you can completely relax. You are never out of control. You can feel completely secure.

Once again, concentrate on your lungs. Picture them in your mind's eye. See if you can see them filled...see if you can see them after you relax. And if your mind drifts away, and you want to, just bring it slowly back to where you are or where you want it to be. You are doing nothing wrong, and anything you do will be a success. And if you hear my voice, that'll be fine...and if you don't, that's fine, too. You can be absolutely sure that your subconscious is hearing every word I say.

Now, perhaps, in your mind's eye--way, way out in space--you can see a word all lit up...and the word is RELAX. Just relax... and now that same word is about a foot in front of your forehead... just see it about a foot in front of your forehead, the word RELAX. And now inside your forehead, see that word, and just relax.

Now, if you want to, pay attention to your left foot, and the toes on your left foot, and your ankle, and let them all relax... and all the cares and tensions of the day just drain down into the floor. Consciously let them relax... and any noise you hear will only serve to deepen your relaxation.

Now pay attention to your right shoulder. All the muscles of your right shoulder, completely relaxed. All the cares of the day drain away and leave you. And consciously

check your right shoulder to see if there's any tension there. Think about it. And now all of the muscles and tendons of your right foot, and the toes of your right foot, and the ankle, just let them relax. And now the calf of your right leg, let it relax. And for this very short time in your mind's eye, perhaps you can see that wonderfully long bone running from your ankle to your knee in your right leg...see how wonderfully straight and long and solid it is...and what a wonderful feat of construction. Let it relax...let all the muscles just relax...and the muscles of your left calf... relax. And way, way out in the future, and way, way into the past.

And this is a process...just like when you were a very, very little person and you didn't know how to ride a bicycle, or tell time, or read. When you were out learning to ride a bicycle, you couldn't even tell how long you were out there because you couldn't tell time, and you didn't know whether there was a difference between writing and printing...and this is also a learning process...learning to relax...learning to be at ease.

And now let all the muscles of your left shoulder completely relax...Let it just droop toward the ground...and rest comfortably against the seat you're in. Let it relax. Now the muscles of your stomach. Let your stomach just hang out...just relaxed. Once again, it's like when you were a very, very little person, just learning how to do all of the things you had to do, like telling time and reading...And now the muscles of your left thigh...This is a time for relaxation...and you don't have to go to sleep...but if you do, that's fine...and if my voice drifts away, that's fine...and if your mind drifts away, that's fine, too. Whatever you do is wonderful. Completely relax.

And now all the muscles of the right thigh...just let them relax. All the tensions of the day just drain out of them into the seat below you. And there's that word RELAX. Consciously in your mind is the word RELAX, way, way out in the past...just in the past...and right behind your forehead.

And all the muscles of your face now...the muscles of your lips, your cheeks, and your forehead, just let them fall toward the ground and your stomach. And your chest...once again, your chest just relaxed, and now your back, and your complete right arm and the fingers of your right hand. And if there's any part of your body that's not completely relaxed already, it soon will be.

You may be surprised to see how relaxed you are already. That may come as a surprise to you...and as I said, if there's any part of your body that's not yet relaxed, it soon will be. And if there's any part of your body that's not feeling as comfortable as it might, concentrate on that part of the body for the next few seconds...just think of it...and send all the endorphins of the brain down in that area. Consciously be aware of any part of your body that's not as comfortable as it might be.

And now all the muscles and sinews and tendons of your left arm and your left hand and the fingers of your left hand completely relax. And all the muscles of your neck and your shoulders and your chest and your buttocks and the whole pelvic area now...Think about

the whole pelvic area...once again your face...and your head...And if my voice drifts away, that's fine, just as long as you're sitting back comfortably and relaxing. Many things are changing in your body, all of which are normal and wonderful, just through your relaxation.

And now, perhaps, if you want to, you'll see yourself at the top of a flight of ten steps going down. You've been at the top of stairs before, and you will be again. So this is completely familiar to you. This is a time when you can just put your trust in the world. You will never be out of control in any way. You can trust...like you did when you were a very, very little person. And everything is going to turn out exactly as you want it to. We're going to walk down these steps together, if you want to, and with every step down you take, you're going to relax just a little bit more.

And now, if you will, you can take the first step down.. and you've taken one step down, and you have nine to go. And with every step down, you relax just a little bit more. And any noise you hear will serve to relax you just a little bit more. And way, way out in the future, and way, way back in the past, and right behind your forehead is that word RELAX.

And now, you take another step down. And with every step down you relax just a little bit more, and now you have taken two steps down, and you have eight steps to go...and take another step down...relaxing just a little bit more with every step you go down. And feel that relaxation in your body...you may be surprised at how relaxed you feel already. And now take another step down, and that's four steps down, and you have six to go. This is a time for relaxation. It's not necessary for you to go to sleep, but if you want to, that's fine. If it happens, that's fine; or if your mind drifts away, that's fine. Nothing that you do is wrong.

Take one more step down. And now you're halfway down the stairs...You have five more steps to go...and you take another step down. And see yourself, consciously see yourself on the sixth step down, and how comfortable you feel, and how secure you feel, and how trusting you feel. And now another step down...and now you've taken seven steps down and you have three to go. And there's that word RELAX shining way, way out in the heavens and behind your forehead at the same time...and you take another step down...and you've taken eight steps and you have two more to go. And now one more step...and you've taken nine steps down and you have one to go... and now take that last step down, and you're all the way down to the bottom of the stairs. And you may be surprised at how relaxed you really are.

And now, if you want to, and it's easy for you to do...perhaps you can see yourself on a lovely, lovely, warm, comfortable beach. And way out in front of you is a calm, calm, very blue ocean. Very calm and very blue. And see if you can smell what the ocean smells like. Really try to smell it. Be there. And the sun is just beating down on your body in a way that can't hurt you under any circumstances...and feel the cool breeze over your body and how comfortable that feels. And hear the ocean lapping on the shore. Listen to what it sounds like. And underneath your feet is the warm sand, just the right

temperature, the way you like it best. And behind you is an enormous beach, friendly and protective and just wonderful.

And now, while you're standing there, perhaps you can see yourself as a very, very little person at a time when you were very happy, very content, and very secure. And feel that happiness, and feel that security, and feel that carefree feeling, and know that that's you...And remember that any noise you hear will just relax you further. And you can call back this feeling of happiness and contentment any time you want to... it's *your* feeling and it's your memory. The only one in the world who has that memory is you.

And now, if you want to, see yourself standing on the beach once again, as an adult... And now, if you want to, knowing that there's a large, comfortable beach towel on the beach to guard your head, see yourself lie down on your back and feel how secure the ground is under you, holding your calves and your backside and your shoulders and your head. Feel how secure that is.

And now, perhaps you'll see yourself surrounded by a lovely golden light. It covers every inch of your body while all the normal functions go on...you breathe very normally and your pores are open, and every normal function goes on. And that lovely, lovely golden light is a combination of all of the healing power of the universe, and all of the healing power of your own body, and all of the healing power of any medication you're taking or radiation you're receiving, or anything you're taking...and that golden light can go anyplace you tell it to.

And now, if you want to, see that part of your body that is not exactly as you want it to be. And direct that golden light to go to that part of your body and surround that area or areas. And know that the golden light surrounding the part of your body that is not as healthy as you want it to be, combines all of the healing power of the universe, and all of the healing power in your body, and all of the healing power of any medication that you're taking. It's an extraordinarily powerful elixir. And any cancer cells that are there are weak and erratic cells and easily defeated. And you can tell the golden light to crush any cancer cells, and to diminish any tumor...and to do anything you want it to do...and it's a powerful, vital, vigorous force and the cancer cells are weak and erratic.

Consciously see the golden light surrounding all of the area where your body is not in the condition you want it to be. And notice...notice how it can bring the endorphins of your brain down into that area and soothe any pain... and help to alleviate any problem that's going on in your body. And tell that golden light to do what you want it to do. It is your golden light. It is going to go where you want it to. And by telling it where you want it to go, you can take some charge of your body.

And now, I'm going to be quiet for a minute or two, and while I'm quiet, perhaps you'll want to continue to think about that golden light doing all the things you want it to do. I'm going to be quiet starting now.

[pause 60 seconds]

And now, with that golden light still within you... that powerful, vigorous, vital golden light still within you, that golden light that combines all of the power of the universe and of your body, and of any medication or radiation or anything else you're taking... with all of that still within you... and completely at your command... from now and forever... perhaps you'll see yourself stand up on the beach. And as you stand on the beach, if you want to... visualize yourself without any physical problem whatsoever, and see what feeling comes over you without any physical problem whatsoever. And know that that's *your* feeling and that you can call on that feeling at any time. You can call on that feeling, or you can call on the golden light, or you can call on the feeling of security at any time without interfering in any way with all of the things that you're doing.

And now perhaps, if you'd like, see yourself at the bottom of the same flight of stairs you just came down, and we 'll walk up those stairs together. When you reach the top of the stairs, you will be back at a place where you started, feeling completely alert, at least as well as you felt when we started, and most likely much better...and take the first step up. And now the second step up [speak slowly here] ...and the third, and the fourth, and the fifth... and you're halfway up... and when you reach the tenth step, you'll be back in the place where you started, feeling completely alert and at least as well as you felt when you started and, perhaps and most likely, much better.

And now you can open your eyes at any time. And now, take the next step up, and you're back at the place where you started... feeling completely alert and at least as well as you felt when you started, and most likely much better... and you can open your eyes at any time.

Note. From "Script For Guided Imagery," by H. H. Benjamin, 1994,

http://www.twc-wla.org/images/GuideImg_files/GuideImg.htm. Copyright 2008 by The Wellness Community. Reprinted with permission.

Additional Online Relaxation Scripts

<http://www.allaboutdepression.com/relax/>

<http://www.healingcancernaturally.com/guided-imagery-for-healing-1.html>

http://creatingminds.org/tools/guided_imagery.htm

http://info.med.yale.edu/psych/3s/imagery_sprt.html

<http://www.holistic-health-wellness.com/Relaxation/MedExperience.htm>

http://csd.mcmaster.ca/natural_high/relaxation.htm

<http://www.support4change.com/change/imagery/scripts/using.html>

APPENDIX J

Criteria for Prolonged Grief Disorder

A. Event Criterion	Loss of a Significant Other (Bereavement)
B. Separation Distress	The bereaved person experiences at least one of the three following symptoms daily, to an intense or disrupting degree: <ol style="list-style-type: none"> 1. Distressing emotional pain, sorrow, or pangs of grief related to the lost relationship. 2. Yearning for the deceased. 3. Intrusive thoughts related to the deceased
C. Cognitive, Emotional and Behavioral Symptoms	The individual must experience 5 (or more) of the following symptoms daily or to a distressing, disruptive, intensity: <ol style="list-style-type: none"> 1. Confusion about one's identity (e.g., role in life or diminished sense of self, feeling that a part of oneself has died). 2. Difficulty accepting the loss. 3. Avoidance of reminders of the reality of the loss. 4. Inability to trust others since the loss. 5. Bitterness or anger related to the loss. 6. Difficulty moving on with life (e.g., making new friends, pursuing interests). 7. Numbness (absence of emotion) since the loss. 8. Feeling that life is unfulfilling, empty and meaningless since the loss. 9. Feeling stunned, dazed or shocked by the loss.
D. Duration	Duration at least six months from the onset of separation distress.
E. Impairment	The above symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities).
F. Relation to Other Mental Disorders	Not better accounted for by: Major Depressive Disorder, Generalized Anxiety Disorder, Post Traumatic Stress Disorder.

Note. From “Complicated Grief Prolonged Grief Disorder: Criteria For Prolonged Grief Disorder,” by H. Prigerson, 2008, <http://www.grief-healing-support.com/complicated-grief.html>. Copyright 2008 by Grief-Healing-Support.com. Adapted with permission.

LIST OF FOOTNOTES

1. From “Factors Considered Important At The End Of Life By Patients, Family, Physicians, and Other Care Providers,” by K. E. Steinhauser, N. A. Christakis, E. C. Clipp, M. McNeilly, L. McIntyre, & J.A. Tulsky, 2000, *Journal of American Medical Association*, 284, pp. 2476-2482. Copyright 2000 by the American Medical Association. All rights reserved. Adapted with permission.

2. From “Professionally Perceived Effectiveness of Psychosocial Interventions For Existential Suffering of Terminally Ill Cancer Patients,” by K. Hirai, T. Morita, & T. Kashiwagi, 2003, *Palliative Medicine*, 17, 688-694. Copyright 2008 by Sage Publishing. Adapted with permission.

3. From “SELF HYPNOSIS: Part 1: Part 2,” by K. Alderson, n.d., unpublished manuscript.

4. From “Progressive Muscle Relaxation,” by E. Jacobson, n.d., http://www.berwickheartsupport.co.uk/html/progressive_relaxation_graeme.HTM. Reprinted with permission.

5. From “The Art and Science of Breathing,” by A. Weil, 2008, <http://www.drweil.com/drw/u/ART00521/three-breathing-exercises>. Copyright 2008 by Weil Lifestyle, LLC. Reprinted with permission.

6. From “Death and How to Prepare For It (#40),” by B. Rose, 2006, <http://www.meditationsociety.com/week7.html>. Copyright 1997 - 2006 by Meditation Society of America. Reprinted with permission.

7. From “Script For Guided Imagery,” by H. H. Benjamin, 1994, http://www.twc-wla.org/images/GuideImg_files/GuideImg.htm. Copyright 2008 by The Wellness Community. Reprinted with permission.

8. From “Complicated Grief Prolonged Grief Disorder: Criteria For Prolonged Grief Disorder,” by H. Prigerson, 2008, <http://www.grief-healing-support.com/complicated-grief.html>. Copyright 2008 by Grief-Healing-Support.com. Adapted with permission.

Copyright Permission for Appendix A (footnote 1)

Subject	Permission Granted - Print.rtf
From	▶ Erin Hinchcliff <Erin.Hinchcliff@ama-assn.org>
Date	Monday, September 22, 2008 11:04 am
To	lmorrell99@shaw.ca

Attachments

Ms. Morrell,

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Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky,

J. A. (2000a). *Factors considered important at the end of life by patients, family, physicians, and other care providers. Journal of American Medical Association, 284, 2476-2482.*

RE: I would like permission to include a list (in an appendix in my Master of Counselling final project paper) of the 26 factors that are considered important at the end of life mentioned in this article.

Best wishes,

Rhonda Bailey Brown
Staff Assistant IV
Publishing Operations

Copyright Permission for Appendix B (footnote 2)

Subject	FW: Permission to use journal extract
From	"Granatowska, Marta" <Marta.Granatowska@sagepub.co.uk>
Date	Wednesday, October 1, 2008 5:16 am
To	lmorrell99@shaw.ca

Dear Linda,

Thank you for your request. Please find this e-mail to be written permission for you to use the below mentioned material from Palliative Medicine in your MA thesis. Please include full referencing to the original publication in the journal.

Kind regards,

Marta Granatowska

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-----Original Message-----

From: Linda Morrell [mailto:lmorrell99@shaw.ca]

Sent: 30 September 2008 20:02

To: Granatowska, Marta; Granatowska, Marta

Subject: Fwd: Permission to use journal extract

Hello,

I am a student (Master of Counselling program) with Campus Alberta (CAAP) and I am seeking permission to use Hirai and colleagues' (2003) list of professionally perceived effective psychosocial interventions in my academic paper. I understand that the Journal: Palliative Medicine has been taken over by Sage.

Hirai, K., Morita, T., & Kashiwagi, T. (2003). Professionally perceived effectiveness of psychosocial interventions for existential suffering of terminally ill cancer patients. *Palliative Medicine*, 17, 688-694.

Thank you,

Linda Morrell

lmorrell99@shaw.ca

----- Original Message -----

From "Educational Permissions" <educational.permissions@hodder.co.uk>

Date Mon, 29 Sep 2008 15:22:47 +0100

To <lmorrell99@shaw.ca>

Subject Permission to use journal extract

Dear Linda,

Virtually all Arnold journals, including *Palliative Medicine*, were acquired recently by Sage, so it would be best to contact them in case they hold copyright.

Their contact details are as follows:

Sage Publications
1 Oliver's Yard
55 City Road
London EC1Y 1SP
f.a.o. Matthew Lambert (Rights Department)

Kind regards,

Nick Wetton (Permissions Administrator)
338 Euston Road, London NW1 3BH
My Ref: M/P/29.09.08

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Permission for Appendices C, D, E (footnote 3)

Subject	Re: relaxation training material
From	▶ Linda Morrell <lmorrell99@shaw.ca>
Date	Friday, April 25, 2008 8:43 am
To	Kevin Alderson <alderson@ucalgary.ca>

Thank you. Have a great day.

Linda

----- Original Message -----

From: Kevin Alderson <alderson@ucalgary.ca>
 Date: Friday, April 25, 2008 8:28 am
 Subject: Re: relaxation training material
 To: Linda Morrell <lmorrell99@shaw.ca>

That would be fine, Linda.

Best,
 Kevin

Kevin Alderson, Ph.D., R. Psych.
 Associate Professor, Counselling Psychology
 Division of Applied Psychology
 Ph. 403-220-6758

Linda Morrell wrote:

Hi Kevin,

My name is Linda Morrell, and I am a CAAP student in the Master of Counselling program. I attended your lectures on "Relaxation Training With Clients" at the CAAP Summer Institute (SI) in 2006, and I would like to have permission to include your "Self-Hypnosis" material that you presented at the SI in my literature review for my final project. The title of my final project is "A Handbook of Interventions and Supportive Counselling Methods for Facilitating a "Good" Death." I think your material is an important strategy that may be helpful to both the dying individual and his or her loved ones/caregivers. If I may have your permission, I will reference it as and unpublished manuscript (i.e., Alderson, K. (2006). *Relaxation training with clients*. Unpublished manuscript), unless you indicate differently. I hope all is well with you.

Linda Morrell

Permission for Appendix F (footnote 4)

Subject Re: Permission to include Progressive Muscle Relaxation Script
From Terry <enquiry@berwickheartsupport.co.uk>
Date Friday, April 25, 2008 1:11 pm
To [Linda Morrell <lmorrell99@shaw.ca>](mailto:Linda.Morrell@shaw.ca)

Hi

Yes you can use the script you require for your masters. If you wish I can e mail you a cd with the progressive relaxation exercise included.

Terry

----- Original Message -----

From: [Linda Morrell](mailto:Linda.Morrell@shaw.ca)

To: enquiry@berwickheartsupport.co.uk

Sent: Friday, April 25, 2008 3:36 PM

Subject: Permission to include Progressive Muscle Relaxation Script

Hello,

My name is Linda Morrell, and I am a student in the Master of Counselling program with Campus Alberta Applied Psychology (CAAP). I would like to have permission to include the *Progressive Muscle Relaxation* script in my literature review for my final project. The title of my final project is "A Handbook of Interventions and Supportive Counselling Methods for Facilitating a "Good" Death." I think this material is an important strategy that may be helpful to both the dying individual and his or her loved ones/caregivers. Thank you.

Linda Morrell

Copyright Permission for Appendix G (footnote 5)

Subject	Re: permission to include Death Meditation Script
From	medit8 <medit8@meditationsociety.com>
Date	Wednesday, April 30, 2008 2:25 pm
To	Linda Morrell <lmorrell99@shaw.ca>

Yes you can use the article.

Thank you

Drweil.com team

Elizabeth

From: Linda Morrell [mailto:lmorrell99@shaw.ca]
Sent: Tuesday, September 30, 2008 12:20 PM
To: editors
Subject: Permission to reprint material from your web site - Re: RE: General Questions & Comments for our Editors

Hi again Elizabeth,

I need to clarify that the permission I was asking for was to reprint the breathing exercises from the Art and Science of Breathing page on your site (<http://www.drweil.com/drw/u/ART00521/three-breathing-exercises>). Also, this is for an academic paper, not a newsletter. I will abide by your guidelines and accurately reference the work and copyright permission. Please email back permission so that I may enclose a copy with my paper submission.

Thank you again for your time.

Linda Morrell

lmorrell99@shaw.ca

Permission for Appendix H (footnote 6)

Dear Linda,

It's fine. You have permission to use it and I hope you accomplish whatever you seek to achieve.

Thanks,
Bob

PS: I authored all the techniques and concepts on our site, but don't usually speak/write/mention that.

Linda Morrell wrote:
Hi Bob,

Thank you for your reply. Attached is how the "Death Preparation Meditation" script is introduced in my paper, followed by the Appendix and ending with how it will be referenced. If you know the name of the author who wrote the script, I will reference him or her - otherwise, I will leave the reference as is. Does this meet with your approval? Thank you for your time Bob.

Linda Morrell

----- Original Message -----

From: medit8 <medit8@meditationsociety.com>

Date: Sunday, April 27, 2008 6:39 pm

Subject: Re: permission to include Death Meditation Script

To: Linda Morrell <lmorrell99@shaw.ca>

Dear Linda,

The way we usually agree to permit republication of articles from our site is if they are printed completely and the site is given recognition as to its source. We do this so that nothing could be taken out of context and presented in a way that doesn't represent what we intended to share. I assume that you want to use only a portion of the content and would like to help you achieve a good result for your project so I will agree to allow the use if we could first review the part where they are mentioned. I hope this will be helpful enough for your project to work as well as you hope it will. Please let me know if this is OK with you. In any event, I wish you well.

Peace and blessings,
Bob Rose, President,

Meditation Society of America

Linda Morrell wrote:

Hello,

My name is Linda Morrell, and I am a student in the Master of Counselling program with Campus Alberta Applied Psychology (CAAP). I would like to have permission to include the *Death Meditation* script in my literature review for my final project. The title of my final project is "A Handbook of Interventions and Supportive Counselling Methods for Facilitating a "Good" Death." I think your material is an important strategy that may be helpful to both the dying individual and his or her loved ones/caregivers.

Thank you,

Linda Morrell

Copyright Permission for Appendix I (footnote 7)

Hi Linda,

Thank you for your inquiry. We are fine with your using Dr. Benjamin's guided imagery script for your final project. Best of luck.

Shannon

Shannon Pao
Events and Marketing Manager
The Wellness Community
919 18th Street, NW I Suite 54 I Washington, DC I 20006
ph: 202-659-9709 I f: 202-659-9301
www.thewellnesscommunity.org

From: Linda Morrell [mailto:lmorrell99@shaw.ca]
Sent: Wednesday, August 13, 2008 11:55 PM
To: Vicki Kennedy
Subject: Fwd: RE: permission to use guided imagery script

Hello,

My name is Linda Morrell. I am a student with Campus Alberta (CAAP). I am looking for permission to use Harold Benjamin's *Guided Imagery* script in my final project for my Master of Counselling degree. Permission via email would suffice. Thank you for your time.

Linda Morrell

lmorrell99@shaw.ca

Copyright Permission for Appendix J (footnote 8)

Subject	RE: FW: RE: Permission for Linda Morrell to include material in her Final Project paper.
From	▶ "Thomas, Karen" <kthomas@apa.org>
Date	Monday, September 15, 2008 9:32 am
To	Linda Morrell <lmorrell99@shaw.ca>

File: Morrell, Linda (author)

Dear Linda,

I apologize for the delay in my response but I have been dealing with multiple urgent requests.

I do not see anything that in the APA volume - Stroebe, M. S., Hansson, R. O., Schut, H., & Stroebe, W. (Eds.). (2008). Handbook of Bereavement Research and Practice: Advances in Theory and Intervention. Washington, DC: American Psychological Association – that looks like what you wish to reproduce from the web site content located at <http://www.grief-healing-support.com/complicated-grief.html>. That is, the entire box with the heading “Consensus Criteria for Prolonged Grief Disorder.”

Therefore, to the best of my knowledge, I do not believe that the content that you wish to use is APA-copyrighted content.

Regards,

Karen Thomas
 Supervisor, APA Permissions Office
 750 First Street, NE
 Washington, DC 20002-4242
 Fax: 202.336.5633
 Ph: 202.336.5541

From: Linda Morrell [mailto:lmorrell99@shaw.ca]
Sent: Wednesday, September 03, 2008 11:05 AM
To: Thomas, Karen
Subject: Re: FW: RE: Permission for Linda Morrell to include material in her Final Project paper.

Hi Karen,

Regarding September 08 Pending File, Yes, I wish to reproduce the entire "box" of the Consensus Criteria for Prolonged Grief Disorder in an Appendix in my paper. I will then direct my readers to visit this site for further information on treatments, strategies, etc. Thank-you for your prompt reply, Karen.

Linda Morrell

----- Original Message -----

From: "Thomas, Karen" <kthomas@apa.org>

Date: Wednesday, September 3, 2008 7:48 am

Subject: FW: RE: Permission for Linda Morrell to include material in her Final Project paper.

To: lmorrell99@shaw.ca

Dear Linda,

Is the content that you wish permission to reproduce that can be accessed at <http://www.grief-healing-support.com/complicated-grief.html>, the table with the heading "Consensus Criteria for Prolonged Grief Disorder"?

On the left hand column are the following headings: A. > Event Criterion, B. Separation Distress, C. Cognitive, Emotional and Behavioural Symptoms, D. Duration, E. Impairment, and F. Relation to Other Mental Disorders.

There is more detailed information in the second column - e.g., for A: Bereavement (loss of a significant other). Please provide the reference "September 2008 Pending File" in any future correspondence regarding this matter.

Regards,

Karen Thomas
Supervisor, APA Permissions Office
750 First Street, NE
Washington, DC 20002-4242
Fax: 202.336.5633
Ph: 202.336.5541

Subject	Re: Submission from
From	Jan Hall <sbi.jan.hall@gmail.com>
Date	Saturday, August 30, 2008 9:03 pm
To	lmorrell99@shaw.ca

Hello Linda

Thank you for your contact. You are of course welcome to use anything from my web site. However, the criteria for diagnosing complicated grief was given to me by Dr Holly Prigerson who developed the criteria. The criteria has recently been published in: Handbook of Bereavement Research and Practice - Advances in Theory and Intervention. Edited by Margaret S. Stroebe, Robert O. Hansson, Henk Schut, and Wolfgang Stroebe, Published by the American Psychological Association 2008

On Sun, Aug 31, 2008 at 12:40 PM, <Jan@grief-healing-support.com> wrote:

On Sat Aug 30 15:39:37 2008, the following results were submitted from the "Contact Form" on grief-healing-support.com:

 First Name: Linda
 Last Name: Morrell
 E-mail Address: lmorrell99@shaw.ca
 Comments: Hello,

My name is Linda Morrell. I am a student in the Master of Counselling program with Campus Alberta (CAAP). I am writing to ask you for permission to include the criteria for diagnosing complicated grief/prolonged grief listed on your site (Grief-Healing-Support.com), in my final project paper. The title of my paper is: " A Handbook of Interventions and Supportive Counselling Methods for Facilitating a "Good" Death." I believe that this information would be beneficial to the bereaved audience, as well as to the professionals who are involved in their care. Thank you for your time.

Linda Morrell
lmorrell99@shaw.ca

 P.S. Also included is the user's IP address below, which we detect at the time the user submits the form. This verifies that each submission is from a unique visitor. Here it is...

68.146.46.5 (Canada)

 Regards
 Jan Hall
griefheal.com